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# The Impact of the COVID-19 Pandemic on the Minnesota Hospice Industry

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**The Impact of the COVID-19 Pandemic on the Minnesota Hospice Industry**

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Thesis Submitted in Partial Fulfillment of the Requirements of the Degree of

**Masters of Arts in Organizational Leadership**

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**St. Paul, Minnesota**

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### **Abstract**

In the year 2020, the respiratory virus SARS-CoV-2, also known as the novel coronavirus-2019, or COVID-19, had a significant impact on the nation's health care system, of which the hospice industry is a part. Research about the specific impact of the virus on this industry is still emerging and to date, no known scholarly qualitative research examines the impact of the COVID-19 pandemic on the hospice industry of Minnesota. This qualitative research project collected the perspectives of hospice industry members in the state of Minnesota, in the form of 5 hospice leader interviews and a survey of 144 hospice industry staff, over the span of 3 months from June to September 2020. Four categories of findings emerged: *Impact on Presence, Impact on Operations, Impact of Communication and Collaboration, and Impact on Morale*. The Change Theory Model of Managing Transitions by William Bridges (1991) served as the theoretical framework to interpret the findings. As strong and effective leadership is critical for organizations to respond effectively to crisis, and toward a more promising future, recommendations and implications for leadership are provided.

## **Introduction**

Throughout 2020, the respiratory virus SARS-CoV-2, also known as the novel coronavirus-2019, or COVID-19, turned much of our world upside down, changing nearly every aspect of daily life. Even a year later, at the time of writing this thesis, the full extent of the pandemic's impacts is still being realized and narratives about the experience of living through the pandemic are still being formed. It is clear that the pandemic has had a significant impact on the nation's health care system. The hospice industry, where I work, is a part of that larger health care system. Research about the specific impact of the virus on the broader hospice industry is beginning to emerge.

In the United States of America, end-of-life care is often provided by the hospice industry. Hospice is a comfort-focused, whole-person care program available to any person with a terminal illness and a life expectancy of six months or less who chooses to no longer seek curative treatments (CMS, 2020). Medicare, Medicaid, and many private insurers cover hospice care. The service focuses on quality of life in the last days, months, or years of life left, promoting spiritual, emotional, psycho-social, cultural, and physical well-being of the individual and their loved ones. Hospice care takes place wherever a person resides, which may include their private home, a group home, or a skilled nursing facility.

Epidemics and pandemics (such as HIV/AIDS, SARS-CoV-1, and H1N1) have historically had a significant impact on the health care industry, including end-of-life care. The COVID-19 pandemic has caused, and continues to cause, significant disruptions to the hospice care industry in the United States, including in the state of Minnesota where I live and work. Demand for hospice services continued during the pandemic as the community experienced an

increased incidence of death and declined health due to the virus. Safety restrictions and precautions prevented hospice services from continuing to provide care as they normally would.

The purpose of this research is to describe the impact of the COVID-19 pandemic of 2020 on the hospice care industry in the state of Minnesota in order to identify recommendations and implications for leaders. I interviewed five hospice directors and surveyed 144 hospice staff in the state of Minnesota, to identify what has been learned during the COVID-19 pandemic, from the perspective of the hospice industry members in the state of Minnesota, United States of America. This thesis's design focuses on how the pandemic was experienced directly, what had already changed at the time of data collection, and informed speculations on what may change about the industry in the long term. There is no known scholarly qualitative research to date on the impact of the pandemic on the hospice care industry, specifically in Minnesota. The hope is that this research can inform organizational and industry responses to future health crisis events.

### **Reflexive Statement**

I have a close and ongoing relationship with the subject of this research. I have been a hospice clinician, specifically a music therapist, working for a major hospice organization in the Minneapolis-St. Paul metropolitan area, Minnesota, for 14 years. The work of end-of-life care has been the primary focus and passion in my career. This passion led me to pursue leadership work in the field of hospice, which drew me to the Organizational Leadership program at St. Catherine University in 2015. My hard work in the program was paying off early in 2020 when I was promoted to a clinical supervisor role in my large hospice care organization.

My new role was set to begin in the first weeks of February 2020. Rumblings of the new COVID-19 virus in Wuhan, China, had begun around the end of 2019 and spread to other areas of Asia and Europe in January. Health care workers followed the story with interest, much like

past outbreaks of SARS or H1N1 Swine Flu. It seemed possible at the time that COVID-19 may never make it to the U.S., or that it would be well contained once we saw cases here.

In preparation for my new hospice supervisor role and the challenges that lay ahead for me, I attended a winter women's retreat in Northern Minnesota, close to the Boundary Waters Canoe Area Wilderness near Canada's border, in January 2020. My friend and I enjoyed a blissful long weekend with minimal access to the internet, skiing, and playing music together. On Sunday, January 26, we made our way back to the Twin Cities and the reality of our busy lives. My friend drove as I checked the news on my phone. I read to her the latest information about the COVID-19 outbreaks. The United States had warned against travel to China as several U.S. Citizens brought the virus back home from Wuhan. Just a few days later, on January 30, 2020, the Director-General of the World Health Organization declared the COVID-19 outbreak an international public health emergency (World Health Organization, 2021).

I began my hospice supervisor orientation in February. Going into March, I was leading three hospice interdisciplinary teams in the Saint Paul metro area and extending into Western Wisconsin. Most of my team members worked remotely in the community, and some were working from our large office in Saint Paul. After many years as a remote hospice field worker, I was just adjusting to office life when we were asked to start working from home. The pandemic had reached Minnesota.

By about mid-March, we knew it was dangerous to be working in closed spaces with large numbers of people. Our usually in-person team meetings were now via video conference, and we arranged "runners" to gather and distribute personal protective equipment (PPE) to our field staff. There were so many unknowns at this stage of the pandemic. How did it spread and how do we treat it? The infections were spreading faster than scientists could find answers.



Conspiracy theories about the virus' origins formed rapidly and began circulating through the internet. Many citizens denied that the virus existed at all, putting them at odds with the desperate efforts of health care workers to contain its spread. Things were getting serious and scary, and fast.

As all of this was happening, I was in the midst of developing my thesis proposal for graduate school. I quickly scrapped my original thesis idea, right before submitting my Institutional Review Board (IRB) application, and changed it to a subject focused on this rapidly unfolding pandemic. It became clear that there would be a significant impact on the hospice industry, and I would be living this impact through my daily work. I also feared that attempting to study something other than the pandemic would be tremendously challenging as this event consumed our world. I updated my IRB application and changed my research question to "What impact has the COVID-19 pandemic had on the hospice industry in Minnesota?"

Into April, I witnessed dramatic changes in how we were able to provide care to our patients and families. In these early days of the pandemic, there were still so many unknowns and much misinformation about how the virus spread and how to treat it. Testing was slow and disorganized. PPE shortages meant healthcare workers were forced to reuse equipment in ways that they would never have been asked to do before. I could hear my staff's fear over the video calls and on the phone. They were terrified that they would spread the virus to their already vulnerable patients and families or that they would bring it home to their loved ones. Staff with certain health conditions needed to be redeployed to office jobs, leaving us with desperate staffing shortages. Staff with school-aged children found themselves suddenly juggling work and homeschooling. It was all so overwhelming. Our bereavement department, usually charged with serving surviving loved ones of our deceased hospice patients in one-to-one or group settings,

saw a spike in demand from both clients and staff seeking emotional support. Our hospice teams were experts in issues of death and grief, but the amount of death and grief caused by the pandemic was unprecedented in their careers.

Then, the economic fallout began. Our health system retracted and braced for the surges in COVID-19 cases. Elective surgeries and clinic activity ceased, causing a massive drop in health system revenue. Minnesota Governor Tim Walz ordered the temporary closure of businesses, which caused a massive spike in unemployment. Even as these orders were lifted in the warmer months, unemployment continued as many companies were forced to close their doors permanently. Many people, myself included, found themselves reduced from a two-income household to one in which there was a sole breadwinner.

Our partnering nursing facilities were panicking during the early months of this pandemic, due to rising outbreaks and death rates. Care facilities put dramatic holds on any visits to their patients, including visits by hospice staff. Additionally, our clients in private homes wanted to minimize exposure and declined most of our services. Many of our staff were unable to visit at all, due to facility visitor restrictions, or client preferences that they not visit, leaving them with a sharp drop in visit productivity.

These visit restrictions threatened the hospice organizations' ability to meet Medicare Conditions for Participation (CoPs) in the Hospice Benefit<sup>1</sup>, thus threatening revenue. Nurses suddenly found themselves forced to fulfill each interdisciplinary team's role, such as spiritual care and social worker roles, something they were not prepared or trained to do. We scrambled to offer more telehealth support, but most clients were not equipped to receive this kind of service

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<sup>1</sup> According to [www.cms.gov](http://www.cms.gov) "The CoPs are the health and safety requirements that all hospices are required to meet. They are a flexible framework for continuous quality improvement in hospice care and reflect current standards of practice."

due to lack of technology equipment, network access, or the skills to manage incoming telehealth calls. The need to furlough staff became inevitable. Just a few months into my new leadership role, I had the painful task of calling other staff members, many of whom were colleagues and friends in my former role as a hospice integrative therapist, to tell them they would be put on extended furlough. Some begged to know if they would be brought back at all. I had to say to them, "I don't know."

The angst of lockdowns and the economic downturn, combined with an increasingly divisive political atmosphere, and centuries-long historical injustices to people of color all contributed to an environment of deep social unrest in the nation. Politically-charged rhetoric around the origin of the virus, with nicknames like "Wuhan Flu" and "China Virus," instigated an increase in racial biases toward Asian American and Asian immigrant people in the country. By August, evidence emerged that Black, Indigenous and People of Color (BIPOC) were disproportionately impacted by the virus (Artiga et al., 2020).

The murder of George Floyd, a black man, by a white member of the Minneapolis Police on May 25, 2020, was the spark that set off a national bomb. Minnesota was the epicenter of its explosion, causing days of protests, violence, looting and burning of buildings in both Minneapolis and St. Paul, all while my teams struggled to provide care to hospice patients in and around the areas of unrest. We continued on despite heartbreak, exhaustion, fear, and uncertainty. The early summer of 2020 was the most difficult period of my career, and I know I am not alone in that sentiment.

Working on this thesis had become a way to cope and create something out of the destruction of this year. My commitments and values as a servant leader have been put through an extreme and laborious test. There were so many aspects of the impact on my teams that were

beyond my control, and I struggled to accept them. By engaging in a broader study of the pandemic's impact on the hospice industry and connecting with other professionals in my network, I found a great deal of validation in my experience and struggles. We were not alone. By connecting, sharing, and supporting each other, we could help each other get through this tremendous challenge. By studying our experience now, I can help leaders better prepare for the next challenge that may come our way. Though not directly aligned with the purpose of this research, for me personally, this thesis has been about finding hope in a time of crisis.

### **Background**

In order to understand the impact of the COVID-19 pandemic on the Minnesota hospice industry, we must first review core elements of the pandemic and the hospice industry. This section reviews both. First, I give a brief summary of the COVID-19 virus and pandemic, as it was understood in 2020. Next, I provide an overview of the hospice care industry in the United States, as well as the state of Minnesota.

### **COVID-19 in 2020**

According to the U.S. Centers for Disease Control and Prevention (CDC), COVID-19 can be spread easily person-to-person via droplet and airborne transmission (2020). Older adults over the age of 65 and people with underlying medical conditions, such as heart disease, lung disease or diabetes are at higher risk for severe illness or even death from COVID-19 (CDC, 2020). CDC research reflected the disproportionate impact of the virus on people of racial and ethnic minorities due to a number of increased risk factors (CDC, 2020). Additionally, people residing in congregate living settings, such as nursing homes, long-term care facilities, prisons, and homeless shelters, are at higher risk because of the close proximity and difficulty managing the spread of the virus. Most confusingly, the virus can be spread easily by individuals who have

no symptoms; infected individuals can experience a wide variety of symptoms, from mild to severe to death, or none at all; and infected individuals can experience symptoms for a short period of time, or for months afterwards, with new symptoms appearing long after initial infection.

Best practices in handling the virus seemed to change day-to-day in the early days of the pandemic. For example, early guidance put more emphasis on the transmission of the virus on surfaces, such as doorknobs and counters. We now know that the main route of COVID-19 transmission is direct exposure to respiratory droplets (CDC, 2020). The CDC, as well as the World Health Organization (WHO) continue to recommend "social distancing," by keeping at least 6 feet away from one another, and wearing masks to prevent the spread of the virus (CDC, 2020; WHO, 2020). In the first half of 2020, health agencies at all levels had pleaded with citizens to help "flatten the curve" in predicted modeling of the outbreak, by way of socially distancing and other precautionary measures, to manage hospital capacity for effectively treating deadly cases of the virus.

The CDC had forecasted that the COVID-19 virus would continue spreading throughout the United States through the duration of 2020 and into 2021 (CDC, 2020). The organization used Ensemble Forecasting to predict infection cases both nationally and by state, to provide guidance on actions needed to prevent the spread. These forecasts accurately predicted an increase in cases as the colder months approached in the fall, with citizens forced back indoors as they moved into the traditionally-social holiday season.

It was not until the latter months of 2020 that scientists had a better idea about how the virus spread, how to prevent the spread, and how to effectively treat the virus. On December 10, 2020, an FDA advisory panel endorsed the first COVID-19 vaccine, and by December 31, 2020,

2.8 million people in the U.S. had received the first of two vaccination doses (American Journal of Managed Care, 2021). The year 2020 closed with a total of nearly 350,000 deaths attributed to COVID-19 and more than 20 million documented infections in the United States. In Minnesota, nearly 5,500 deaths from COVID-19 occurred in the year 2020 (Minnesota Department of Health, 2021). At the time of this writing (May 14, 2021), there had been 581,573 deaths in the United States, 7,367 of them in Minnesota (CDC, 2021).

### **Hospice Care in the United States and Minnesota**

Hospice plays a critical role in dignified end-of-life health care. Since 1985, the Hospice Benefit has been a permanent care option of the United States Medicare program (National Hospice and Palliative Care Organization, 2020). The Centers for Medicare and Medicaid Services (CMS) define hospice as comfort-focused, whole-person care available to any person with a terminal illness and a life expectancy of six months or less who chooses to no longer seek curative treatments (2020). Hospice care is a part of the larger health care system. It collaborates with a number of other partnering care systems, including palliative care, home care, geriatrics, and long-term care. In this section, I summarize what hospice care is, and who they serve nationally in the United States and in the state of Minnesota.

Hospice care takes place anywhere a person resides, which may include their private home or a skilled nursing facility. A sizeable interdisciplinary hospice care team is involved in ensuring whole-person care to the terminally ill individual, their family, and caregivers. The care team consists of a physician, nurse, counselors, social workers, home health aides, volunteers, and various other skilled services (CMS, 2020). Typically, these providers would come to the patient's residence and provide intimate direct care and face-to-face supportive presence several days a week.

According to the National Hospice and Palliative Care Organization (NHPCO, 2019), 1.49 million individuals utilized the Hospice Medicare benefit in 2017. Of those individuals, 62.4% were over the age of 80 years old, and the majority had a primary diagnosis of either cancer, circulatory and heart diseases, or dementia. A qualifying hospice patient may have many other comorbid diagnoses that contribute to their physical decline. Based on these statistics of age and medical frailty in hospice, and the risk factors outlined by the CDC, we have known since early in the pandemic that the vast majority of hospice patients are at higher than average risk for contracting and dying earlier than expected from the COVID-19 virus.

The state of Minnesota has a robust hospice care industry, with a high utilization rate of hospice services compared to other states. In 2017, Minnesota ranked twelfth of all fifty states for the number of Medicare decedents who were receiving hospice care when they died, at 52.7% (NHPCO, 2019). In the calendar year 2016, 23,917 Medicare patients received hospice care in the state of Minnesota alone, totaling about \$277,534,742 in hospice benefit payments. According to the Minnesota Department of Health (2020) at the time of this writing, 93 Licensed Hospices operated within the state. There were 75 Medicare Certified hospices and 15 Residential Hospices.

### **Review of Literature**

In this section I review the existing literature that is related to my research of the impact of the COVID-19 pandemic on the hospice industry of Minnesota. First, I discuss how the end-of-life care community has handled health crises events in the past. Then, I delve into research related to the impact of the pandemic on the health systems.

### **Impact of Past Health Crises on the Hospice Industry**

The COVID-19 pandemic is not the first crisis that the hospice care industry has weathered, although it is unique in many ways. We can learn a great deal from how the end-of-life care industry has handled past pandemics, as well as natural and human-made disasters. While we have made great strides in learning and preparing for future crises, we still have a long way to go in adjusting to the new challenges as they arise.

The hospice industry's first pandemic occurred shortly after the U.S. Medicare Hospice benefit was authorized by the 1982 Tax Equity and Fiscal Responsibility Act (TEFRA) (Davis, 1988). The HIV/AIDS pandemic brought about fear and paranoia in the early days when the virus's transmission was not fully understood. Additionally, there was a significant stigma that came with infection. Pace and Stables (1997) found that hospice patients with AIDS reported significantly lower spiritual well-being than patients with other types of terminal illness. They cited poor systems of support, social and religious rejection due to homophobia, and the younger age of dying as some of the reasons behind this low spiritual well-being.

The stigma and fear of the HIV/AIDS pandemic continued on for many years and was experienced around the globe. In 2012, Makhele and Mulaudzi interviewed ten South African families receiving hospice care support to their loved one who was dying of AIDS. The family members expressed feelings of grief, rejection, guilt, and anger upon diagnosis. Several interviewees expressed that they felt hospice care was more compassionate and empathetic than the type of care they received in the hospital.

The international hospice industry had experienced the impact of another pandemic in the early 2000s: The first version of Severe Acute Respiratory Syndrome (SARS, now known as SARS-CoV-1). Chen et al. (2006) documented inpatient hospice ward utilization rates during the



SARS outbreak of 2003 in Taiwan. They noted that more than half of all SARS patient cases were hospital-related and that it made sense when families did not want their loved one to die in a hospital-based hospice ward. Their data reflected a clear drop in inpatient hospice ward utilization during the peak of the pandemic, with a 3-month lag in recovery for those remaining in the hospital (p. 3). Anecdotally, they shared their suspicions that a combination of family and hospital policy decisions were driving this decrease in utilization.

While Taiwan experienced a reduction in hospice utilization due to SARS-CoV-1, Downar and Seccareccia (2010) expected a “surge” in discharges to palliative care services in the wake of the Influenza A subtype H1N1 pandemic. They called for a palliative care plan in response, anticipating that H1N1 patients would overwhelm the hospital system, and there would be an increase in palliative care referrals as health care workers triaged those least likely to survive towards comfort cares rather than curative treatments.

The literature revealed a theme of resource scarcity in the scope of a health care crisis. Several scholars (McGrady et al., 2013; Marzo et al., 2009; Emanuel et al., 2020; Downar & Seccareccia, 2010) discuss the possibility of triaging care decisions to deny the medically frail curative treatment during a pandemic that overwhelms the health care system. The assumption, by many of these authors, is that these decisions would increase the number of patients referred to hospice and palliative care services. Additionally, several authors (Marzo et al., 2009; Emanuel et al. 2020; Downar & Seccareccia, 2010) discussed using an ethical framework to guide decision-making when resources are scarce, to maximize benefits to life, and minimize risks or losses. The authors emphasized the impact of this ethical decision-making, choosing to save some and not others, on health care practitioners’ mental health.

The literature also indicates the need for disaster planning by end-of-life care organizations. Marzo et al. (2009) published a research review in response to the need for disaster planning for community palliative care needs in case of a mass casualty event when resources may be scarce. Their research was inspired by significant disaster events like the destruction of the World Trade Center Twin Towers of September 11, 2001, and the devastation from Hurricane Katrina in the summer of 2005. In addressing mass casualty events, Marzo et al. (2009) stated importantly,

While the primary goal of an organized and coordinated response to a mass casualty event should be to maximize the number of lives saved, civil society demands a secondary goal of minimizing the physical and psychological suffering of those whose lives will probably be shortened by such an event (p. 201).

### **Impact of COVID-19 on the Health Care System**

The extant literature describes the impact of past health care crises on the hospice industry, while also informing current studies of the COVID-19 pandemic's impact to our U.S. health care systems. These current studies echo the earlier studies. In this section, I review the emerging research about COVID-19's impact to various health care systems which partner with the hospice industry. I discuss impacts to system overwhelm and resource allocation, congregate care settings, home-based care, social isolation, telehealth, and health care worker health. I also briefly note the need for more research.

#### ***System Overwhelm and Resource Allocation***

A review of emerging research reflected a concern that COVID-19 could overwhelm the health care system and cause a scarcity of resources across healthcare systems. Like Downar and Seccareccia (2010) expected with the H1N1 pandemic, many authors expected a surge in

COVID-19 cases would overwhelm the health care system and cause an increase in hospital discharges to hospice and palliative care. In a letter to the editor of the *Journal of Pain and Symptom Management*, Physicians with the Veteran's Affairs Ann Arbor Geriatric Research Education and Clinical Center, Victoria D. Powell, MD, and Maria J. Silveira, MD (2020) provide a thought-provoking perspective on the role of Palliative Care in response to the COVID-19 pandemic. Not only did they predict a surge in referrals to hospice and palliative care services due to the pandemic, but they also recommend palliative care teams encourage early enrollment to hospice (p. 2).

Powell and Silveira (2020) predicted that as resources for life-sustaining treatments, like ventilators, became scarcer, the older and more medically frail patients would be denied this treatment. They referenced the heartbreaking decisions for the rationing of resources that were shared by Italian and Chinese doctors earlier in the COVID-19 pandemic. Importantly, they noted, "Rationing of health care is antithetical to the American mindset and is likely to provoke intense emotions among patients and families who are triaged" (p. 2). Powell and Silveira both recommend that palliative care teams avoid participation in the design of guidelines for rationing care, perceiving them as part of a "death panel," which would erode trust from patients and families when they require more emotional support than ever. They also recommended that patients be discouraged from coming to the hospital to avoid exposure and potential infection, and instead, encouraged to stay home with hospice support services.

In addition to the scarcity of treatment supplies and resources, the U.S. health care system was rocked by a sudden jump in the need for personal protective equipment (PPE) like masks, gloves and gowns, which caused major challenges in maintaining and distributing resources. In most demand were the specialized respirators for professional use, the fitted N95 mask (Fischer

et al., 2020). The N95 or similar respirator is required by the Occupational Safety and Health Administration (OSHA) for health care workers who are in contact with suspected or confirmed cases of COVID-19 (2020). Although the N95 was originally designed to be “single-use,” health care professionals found themselves reusing and rotating through the respirators due to national shortages (USFDA, 2020).

Scarcity of resources created a number of ethical challenges as the pandemic raged on. Emanuel et al. (2020) summarized ethical theories to inform their recommendations for practitioners on how to fairly allocate resources if or when scarcity events occur during the COVID-19 surge. In addition to the alarming lack of PPE, hospital beds, ventilators, and staff needed to address the needs of COVID-19 patients, they pointed out that the testing of pharmaceutical treatments and vaccines to prevent the viral infection would take more time than was available to avoid a health system crisis.

Emanuel et al. (2020) noted the psychological trauma that clinicians are likely to face in making these difficult ethical decisions. They recommended triaging policies be created by upper leadership to take the decision burden off the clinicians:

Limited time and information in a COVID-19 pandemic make it justifiable to give priority to maximizing the number of patients that survive treatment with a reasonable life expectancy and to regard maximizing improvements in length of life as a subordinate aim (p. 4).

They encouraged all patients who faced the prospect of intensive care to document their wishes in an advanced care directive. This would help practitioners understand whether a patient would want a ventilator in the first place or if they would want to focus on comfort cares like hospice.

### *Congregate Care Settings*

It would be difficult to separate the impact of the COVID-19 pandemic on the hospice industry without including the impact to congregate care and long-term care settings like nursing homes, group homes, and assisted living facilities. The close quarters of congregate care living settings, as well as the majority medically frail residents of these settings, created an environment where the virus could spread and kill rapidly. Because hospice care serves patients at end-of-life in whatever setting they call home, a large portion of hospice benefit recipients are served in congregate care settings.

Despite preparations and experiences from other outbreaks, this pandemic caught the long-term care industry off guard. Dosa et al. (2020) addressed the impact of the COVID-19 pandemic on Long Term Care (LTC) and other types of congregate housing facilities. They recognized that, at the time their article was prepared in early March 2020, the recommended precautions were evolving rapidly. They also made numerous connections to past influenza outbreaks, which have ravaged congregate living settings for the elderly in previous years, and they discussed the dire need for risk mitigation actions to prevent further spread of the virus.

Respiratory infections have a history of causing harm in congregate care settings and are among the top three most common types of endemic infections found in nursing home residents, according to Geriatricians Montoya and Mody (2011). Of the types of respiratory infections they reviewed, influenza was the most common epidemic infection reported in nursing homes, which can lead to pneumonia and increased risk of death. Montoya and Mody (2011) also discussed the importance of annual immunizations to reduce mortality from seasonal outbreaks of influenza, and the most critical action in controlling the spread of infections: hand hygiene (p. 892).

Congregate care facility staffing challenges and complications arose almost immediately during the pandemic. Dosa et al. (2020) note that maintaining adequate staffing levels is tremendously essential in nursing homes and assisted livings. They recognize that many LTC workers live "paycheck-to-paycheck" and may be motivated to come into work even when they are sick. They emphasize that "providing a work environment that allows healthcare workers to call out without repercussions will be critically important" (p. 570). They also note that "training staff and visitors on how to minimize their risk for picking up [the] virus in the community and the facility and transmitting it to others will remain our most important tools" (p. 571).

### ***Home-Based Care***

Providing safe home- and community-based care, as hospice does, has always been a challenge. The COVID-19 pandemic was certainly no exception. Similar to challenges in other areas of health care, infection control and rationing of Personal Protective Equipment (PPE) resources are both significant challenges in home- and facility-based care with the medically frail. The biggest driver of these safety challenges is the lack of environmental control that home care workers face in the field. Additionally, safety equipment may be less accessible or in shorter supply than if one was working in a health care facility.

Another review of common infections took a look at patient risk factors in home health care settings, where care is provided in residential settings rather than in a facility. Shang et al. (2014) discussed the challenges of primary caregivers in the home who have little to no formal training in infection control procedures. Primary caregivers may be family members of all ages and ability levels, as well as friends, neighbors, or independently hired care staff. Unlike in facilities with a controlled environment and skilled staff, infections may be more prevalent in home care patients, despite training efforts by professional-level home care staff (p. 408). Shang

et al. (2014) call for a more standardized surveillance system to monitor home care-associated infections, similar to how there is a system for all skilled nursing facilities (p. 483).

Concerns about scarce Personal Protective Equipment (PPE) also extends into the home-based care setting. The use of PPE is imperative for home care and hospice workers to prevent the spread of infections from home site to home site, and to protect themselves from exposure. Leiss, Sitzman, and Kendra (2011) surveyed home care and hospice nurses to ask them about what PPE they had available to them in their work. They found that, despite the "Universal Precautions" guidelines created by the Centers for Disease Control and Prevention (CDC) for preventing exposures to infectious diseases, and the standards set by the Occupational Safety and Health Administration (OSHA), home health and hospice workers did not always have access to enough PPE to follow the guidelines. This is different than and lacking compared to what healthcare workers in hospitals experience with PPE availability. They noted that "because the patient's home is not under the control of the employer, home health agencies may be exempt from the requirement to enforce employee's use of PPE" (p. 124). These PPE access challenges continued through to the COVID-19 pandemic.

### ***Social Isolation***

Traditional work with those at end-of-life can be particularly intimate, requiring close proximity to be effective. It involves every level of dependent care, including bathing and feeding, changing drainage tubing, and keeping wounds clean, as well as the intimacy of hand holding or massage. With the COVID-19 pandemic, health care practitioners scrambled to minimize exposure by isolating the medically frail.

As noted earlier, isolation began with keeping the medically frail out of hospitals and sending them home. In a letter to the editor of the Gerontological Society of America, medical

professionals Tzyy-Guey Tseng et al. (2020) shared their experience of the COVID-19 pandemic's impact on disabled and hospice home care patients in the country of Taiwan. They noted the importance of keeping vulnerable patients out of the hospital to minimize the amount of exposure they might experience from external caregivers (p. 1). At the same time, they recognize the additional burden this action may place on caregivers in the home, including caregivers from other countries who may experience a communication gap in understanding infection control procedures (p. 1). Additionally, they note the difficulty of differentiating expected symptoms of the patient's decline (such as fever and shortness of breath), from symptoms of the COVID-19 virus, while minimizing the amount of staff observing the patient (p. 1).

As the pandemic has worn on, the detrimental effects of social isolation on our most vulnerable populations were better realized. The combination of social distancing practices and congregate care visitor restrictions has taken its toll on those who are both most at risk for catching COVID-19 and most vulnerable to the adverse health effects of loneliness (Ouslander & Grabowski, 2020). Harden et al. (2020) point out that social isolation and loneliness are attributed to increased mortality rates and increases in mental health challenges. In a review of three case studies, they noted that elderly patients separated from their advocates (like family members and full care team) resulted in a loss of autonomy and feelings of independence (p. 5). The researchers found that creativity is key to addressing these challenges and balancing safety with well-being (p. 7).

### ***Telehealth***

In an effort to reduce the negative impacts of isolating patients and their caregivers, technology advances lurched forward to meet the skyrocketing demand. The health care industry



had been slowly moving towards using more telehealth or telemedicine vehicles for providing care prior to the pandemic. COVID-19 forced health care to launch head first into this kind of service. Telehealth or Telemedicine has been identified as the most promising way to stay connected with patients during the pandemic, however not all patients, families or even providers have the means or ability to connect this way.

The rapid move towards telemedicine posed a number of issues in the hospice industry. The most immediate challenge identified by Brody et al. (2020) in telemedicine had been reimbursement (p. 9). At the time of their article publishing, not all insurance providers accepted alternative telemedicine support in their reimbursement structure. As providers increased their efforts to maintain contact with their patients using telemedicine, it appeared that they were actually making less contact and not meeting regulatory requirements (p. 11). Another major challenge of moving to telemedicine is that it exacerbated the existing disparities in equitable care and challenged health care privacy. Individuals who did not have the equipment, network access, or technologic skills were essentially left out of many care options. Brody et al. (2020) recommend continued efforts to update telemedicine policy to meeting the changing demands brought by COVID-19.

### ***Health Care Worker Health***

Emerging research indicates that Health Care Workers (HCW) have endured significant physical and mental health impacts due to serving their communities during the COVID-19 pandemic. While HCW experienced a disproportionate level of stress during the pandemic, coping challenges were experienced throughout the general population. Asmundson et al. (2020) found that people who had pre-existing anxiety and other mood disorders prior to the COVID-19 pandemic exhibited a higher stress response to the pandemic. They found that individuals

suffering from this higher stress response were more likely to self-isolate than others who did not have anxiety or other mood disorders. Additionally, they pointed out the need for specially-tailored mental health interventions for this group during the fallout of the pandemic.

Health Care Worker health was disproportionately impacted by the stress of the pandemic. Pappa et al. (2020) found in their systemic review that a significant amount of HCWs experienced mood and sleep disorders, such as anxiety, depression and insomnia, as a result of working during the pandemic. They also noted a higher prevalence of these detrimental effects in nursing staff, more so than in doctors (p. 906). Their findings call for more attention to the needs of health care workers and more support to “enhance resilience and mitigate vulnerability” (p. 907). Korkmaz et al. (2020) revealed very similar results as Pappa et al. (2020), including sleep disturbances and anxiety, as well as a disproportionate negative impact on nurses versus other types of health care professionals. Additionally, Korkmaz et al. (2020) found an adverse effect to problem-solving skills in the healthcare workers, which contributed to a decrease in HCW quality of life.

### ***The Need for More Research***

Research relating specifically to end-of-life care during COVID-19 was just beginning to reveal itself at the time of this literature review, and captured a great deal of speculation about what the pandemic’s impacts might be. Etkind et al. (2020) of the Cicely Saunders Institute of Kings College, London, provided a rapid review of evidence to inform hospice and palliative care response during the Covid-19 pandemic. They found that the research reflected a general lack of preparedness and experience with managing pandemics in the United States and Europe, with most studies occurring in Asia or Africa (p. 7). They conclude that more research is needed,

and that hospice and palliative care need to be more integrated into future pandemic planning (p. 10).

This peer-reviewed research on the role of hospice and palliative care during the COVID-19 pandemic does help inform where we might go and how the industry may be impacted, but some of the long-range effects are yet to be seen. It may be that we will not fully know, for years perhaps, what the impact will be. We must continue gathering more data on what is happening now, to help us learn and adapt, and to prevent premature loss of life in the future.

### **Theoretical Framework**

For this thesis, I chose to frame the data and discussion using Change Theory principles. There are several change theories and models to choose from, especially in the world of organizational leadership. Many change theory models focus on change as a planned effort when an individual or organization agrees to achieve a long-term goal and decides to work through the discomfort of a strategic change towards that goal. The COVID-19 pandemic was not planned. It was thrust upon us in a way that none of us would have chosen to participate in. In many ways, the change we were experiencing was against our will, thus increasing the change's psychological toll.

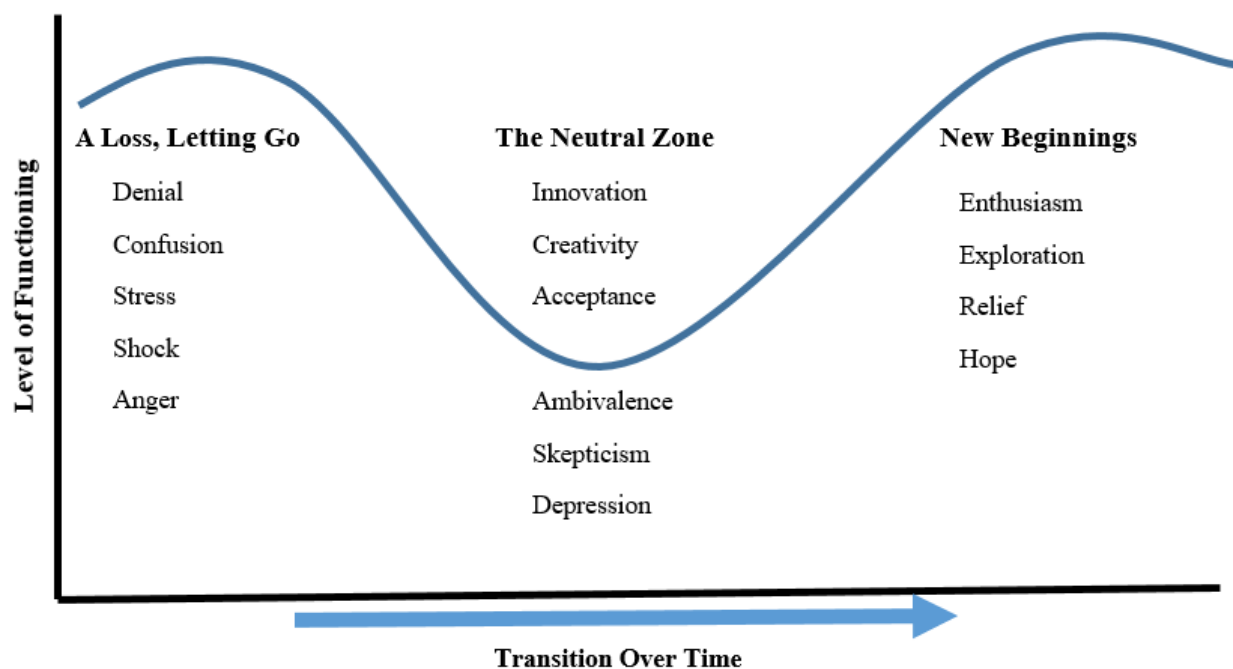
Due to the pandemic's psychological and social impacts, I have chosen to focus on the Change Theory Model of Managing Transitions by William Bridges (1991). The Bridges Model includes three phases of transition through change:

- 1) Loss
- 2) The Neutral Zone
- 3) New Beginnings

I have presented a U-shaped diagram based on the Bridges Model, in Figure 1. According to the Bridges Model, the start of a change begins with a Loss, and letting go. Letting go may include giving up old relationships, identities, ways of thinking, and operating. It may result in feelings of shock, denial, stress, and confusion. For some, it may result in feelings of anger. Change from the Loss may be experienced as positive or negative and still begin with a letting go of something. For example, at the personal level, having a baby, going through a move across the country, or going through a divorce could result in the loss of old lifestyle habits and relationships. For organizations, and even whole societies, change could begin with the loss of a long-time leader, adopting a major new technology, or abolishing a practice that benefited some and harmed others.

**Figure 1**

*Bridges (1991) Three Phases of Transition*



The Neutral Zone is between the Loss and New Beginning, where various experiences could occur, in what Bridges likes to refer to as a "psychological no-man's-land." The Loss may

have been abrupt, and this Neutral Zone may go on for some time, as the New Beginnings are slowly realized. Transitioning into the Neutral Zone is characterized by confusion, not knowing which way is up. What happens from there depends on the circumstances and the individual(s) involved and can dictate the New Beginnings results.

In the U-shaped diagram (Figure 1), the Neutral Zone is represented with a significant decrease in functioning. Organizational change leaders may interpret this level of functioning as it relates to productivity and engagement. Individuals may experience this as a change in mood and ability to perform in their day-to-day lives. While each change will result in some level of decreased functioning, the severity may vary. On the low levels of functioning, there may be ambivalence, skepticism, and depression. On the high levels of functioning, there may be creativity and innovation in response to the change event.

Due to the varied potential levels and pathways of functioning, there is an excellent opportunity during the transition towards a New Beginning. There is an opportunity for revitalization and renewal, perhaps realizing the New Beginning at a higher functioning level than before the Loss occurred. The Neutral Zone can also be a dangerous place where New Beginnings take shape at a lower level of functioning than before. The influence of many factors can dictate the potential outcomes, including but not limited to support systems, resilience, and leadership.

Moving out of the Neutral Zone and towards New Beginnings will take time and should not be rushed. If the move out of the Neutral Zone is too rapid or abrupt, ineffective solutions or maladaptive coping behaviors may replace the old ones and leave the individual or organization poorly functioning, perhaps worse than before the change began. The New Beginnings will be

adopted gradually, not all at once. Whereas the Loss may have been an abrupt change, the New Beginning requires time and a transition.

Professionals in end-of-life care may recognize similarities between Bridge's Transition Model and Swiss psychiatrist Elizabeth Kubler-Ross's Five Stage Grief Model in her pivotal 1969 book *On Death and Dying*. Both models begin with a loss. Kubler-Ross followed the loss with the stages of Denial, Anger, Bargaining, Depression, and then Acceptance. Acceptance is the process of exploring and moving forward. Both models capture a significant change imposed on an individual or group and recognize the psychological struggle involved in recovering from the change's losses. Whereas Kubler-Ross focused namely on the individual experience, Bridges expands this model on an organizational level.

### **Method**

This qualitative research study sought to answer the question, "What impact has the COVID-19 pandemic of 2020 had on the hospice care industry in Minnesota?" To effectively answer my research question, I began with semi-scripted qualitative interviews targeting a small sample of hospice leaders. I then used the results of the interviews to design a larger-scale hospice staff survey.

According to O'Leary (2017), the qualitative approach is tied to a set of assumptions related to subjectivism, captured in the form of words, experiences, and observations which are not quantified (p. 8). I chose qualitative methods to design my research because it accepts the realities of multiple perspectives and belief systems within a group of people (p. 142). Additionally, qualitative research recognizes the researcher's relationship with the research subject. The method demands the researcher engage in a strategic analysis process to ensure credibility in the conclusions (p. 9).

I used interviews to capture a small group of hospice leaders' experiences and observations through open-ended questions and a semi-scripted approach. Using the Phased Approach, as described by O'Leary (2017), I used the interview method at the start of my project to inform the design and implementation of the second aspect of my study, a qualitative online survey (p. 168). The survey collected data from a larger sample of hospice industry workers through a combination of closed- and open-ended questions to capture that group's experiences and observations. The challenge in using the Phased Approach is to integrate the findings from both methods (p. 168). These two data collection methods combined validate and expand the data.

In defining both "industry" and "impact," I focused my research primarily on the human experience. I use the word impact as both a noun ("the impact"), and at times as an intransitive verb ("impact on"). In this use, Merriam-Webster (2021) defines impact as "the force of impression of one thing on another; a significant or major effect." The industry in Minnesota is defined as the collection of hospice organizations, its leaders, and its workers who provide hospice care services to Minnesota residents. I intentionally excluded researching the industry's financial impact due to a high level of competition among hospice organizations in the state and the low likelihood that I would find participants willing to share this information. The impact of the pandemic will be captured by the affected individuals making up these hospice care organizations.

### **Participant Selection**

There were two categories of participants in this study. First, I interviewed hospice leaders, and then I surveyed hospice staff. I describe each population in this next section.

It is important to note that both categories of participants are a convenience sample, not random. According to O’Leary (2017), convenience sampling is participant selection based on what is convenient for the researcher (p. 211). Strengths of a convenience sample include obtaining a larger number of participants in a smaller amount of time while using very limited resources. Limitations include decreasing the validity as a non-random population sample while also allowing for bias. This bias may also be challenging to measure and account for in the analysis.

### ***Hospice Leaders***

My interviews with hospice leaders included people who held Directors of Hospice positions, or similar leadership roles, from five out of at least 93 different licensed hospice organizations operating in the state of Minnesota. The Director of Hospice is often considered an executive or operations leadership role and may be directing the organization as part of an extensive health system or a standalone hospice organization. For this research project, I did not include hospice Medical Directors (physicians) in these interviews. Instead, they could participate in the hospice staff survey as roles that interact more directly with hospice patients and families.

I recruited hospice leader participants from the Minnesota Network of Hospice and Palliative Care (MNHPC) membership roster. I contacted the hospice leaders using email and phone calls. See the attached Recruitment Statements (Appendix A). Each of the five leaders represented a mix of organization sizes (determined by service area and the number of patients served) and a combination of urban and rural settings served by their organization. I was professionally familiar with one of the five interview participants. Due to the low number of



interview participants and the low number of hospice Directors in the state, I did not collect potentially identifying demographic data on this group.

### *Hospice Staff*

For the hospice staff surveys, I garnered the assistance of MNHPC to recruit participants, using their member newsletters and social media posts to invite members to participate. Additionally, I used my extended professional network via email and social media to increase participation. In total, 144 individuals participated in the survey, with 119 participants completing all the survey questions. The participants represented a variety of roles within their hospice organization. The majority of participants were nurses, at 31.3%. About 70% of participants have worked in hospice care for less than ten years. Forty percent of survey participants served primarily urban areas, and 50% served a mix of urban and rural areas. Urban areas are defined as densely populated communities, such as Minneapolis, Saint Paul, Rochester, and Duluth. Only 9% of survey participants served primarily rural areas.

Rather than identify the name or specific location of the organization the participants worked for, I asked them to identify the size of their organization by average daily census (ADC). ADC is the amount of hospice patients served by the organization on any given day. More than half of the participants worked for a large or very large hospice organization, with an ADC greater than 250. Only nine participants represented a small hospice program with an ADC of 50 patients or less. See Table 1 for details on participant demographics.

**Table 1***Participant Demographics*

Identifier	<i>n</i>	%
Role in hospice organization		
Physician	5	3.5
Nurse Practitioner	2	1.4
Nurse	45	31.3
Health Aide	4	2.8
Social Worker	18	12.5
Spiritual Care Provider	10	6.9
Bereavement Counselor	5	3.5
Volunteer Coordinator	3	2.1
Therapist (Physical, Massage, Music)	26	18.1
Administrative Support	6	4.2
Supervisor or Manager	17	11.8
Director	1	0.7
Volunteer	1	0.7
Intern	1	0.7
Hospice experience in years		
Less than one year	8	5.6
1-5 years	51	35.4
6-10 years	42	29.2
11-20 years	25	17.4
21-30 years	14	9.7
More than 30 years	4	2.8
Hospice service area		
Mostly urban	58	40.3
Mostly rural	13	9.0
A mix of both	73	50.7
Hospice size by average daily census		
Small (1-50)	9	6.3
Medium (50-250)	53	36.8
Large (250-500)	39	27.1
Very Large (over 500)	43	29.9

Note. *N* = 144

## **Data Collection**

I conducted interviews and surveys for this research. My original intention was that my data collection would consist exclusively of interviews with about ten hospice leaders for my thesis. My participant selection began first, with hospice leader interviews taking place between mid-June and the end of August 2020. As the pandemic raged on through the summer, I found it increasingly difficult to secure time with these leaders for a live interview. I had considered a staff survey since the beginning of my proposal. I quickly enacted a plan to enrich my data and provide a more well-rounded perspective towards the research question. I created the survey based upon the results of the interviews, and opened it to participants between August 11 and September 13.

Concerning the data collection, it is important to note when I collected the data and to map those dates onto a timeline of what was happening with the pandemic and other social forces occurring in Minnesota. Before the interviews took place, Minnesota had grappled with business shutdowns and Personal Protective Equipment (PPE) shortages. Many workers had been moved to working from home, were furloughed, or laid off. Some workers were juggling the needs of children who were unable to go to daycare or were being schooled virtually from home. Testing for the virus had begun in March 2020, still with a slow or inconsistent turnaround time for results, while many ability-to-work guidelines hinged on those results.

Most congregate care facilities, like nursing homes, had begun closing their doors to visitors in March 2020. The visitor restrictions inconsistently ranged from no visitors at all, to only hospice nurses, or only those who could produce negative test results. Most facilities did not allow family to visit at all unless death appeared imminent. With staff limitations and shortages,

it was difficult to determine when death was imminent and some families were unable to visit in time to say goodbye to their loved one.

In May 2020, extreme social unrest began in Minnesota following the murder of George Floyd. The height of the protests, demonstrations, and large-scale destruction of property in the Twin Cities occurred from about May 26 to June 1. The first of my interviews for the study began just two weeks later, while piles of rubble were still smoldering in Minneapolis and our communities were still tense with fear and anger. As the turmoil's epicenter continued locally, it extended to a worldwide movement as the summer progressed.

### ***Hospice Leader Interviews***

Each participant committed to an hour-long semi-scripted interview after giving consent and signing a consent form. Each answered six open-ended prompts and questions (see Appendix B) about their experience of the pandemic's impact on their industry. The open-ended interview questions allowed participants to decide what information or opinions they would share, in their own words (O'Leary, 2017, p. 235). The first prompt of the interview instrument, "Tell me about your experience..." was used to get the conversation started. The other prompts were in the form of questions to identify the interviewee's specific experiences, learnings, and opinions. All of the prompts and questions assumed the participants experienced or observed some impact from the COVID-19 pandemic.

Interviews took place virtually due to infection control policies with both the State of Minnesota and the St. Catherine University Institutional Review Board (IRB). The interview data was kept confidential through de-identification processes, including pseudonyms for each interview participant and omitting names from all data collection resources (calendars, file

names, etc.). I used the electronic transcription service, Rev.com, which ensures confidentiality, to capture the interview content word-for-word and create complete transcripts.

### *Hospice Staff Survey*

After completing most of the hospice director interviews, I used the interview questions and director responses to inform a hospice staff survey design (see Appendix C). I began my survey with demographics questions to identify the role participants played in their hospice organization, the length of time they had worked in hospice care, the population density of the area they served, and the size of their organization by the average daily census. Next, I developed a mix of closed and open response questions based on the interview instrument and the leader interview responses. Open response questions allowed participants to choose what they wanted to share, in their own words. Closed responses ask that a participant chose from a set range of predetermined responses, making the responses easier to code and statistically analyze (O’Leary, 2017, p. 235).

After the demographics section, the survey listed 14 different potential challenges that hospice staff may have experienced and identified “other” challenges not listed. I presented the 14 challenges in two ways: first, to classify the degree that the challenge impacted the participant, and second to identify the list’s top three challenges. Next, I asked that participants provide their perspective on how their hospice organization, their state’s industry, and their state government handled the pandemic, including open-ended questions about what went well and what did not go well. I then asked participants what they thought would permanently change because of the pandemic and what was still left unresolved. Finally, I provided an open opportunity to add any other thoughts they wanted to share.

I utilized the survey platform SurveyMonkey to design, implement, collect and analyze the survey responses. Responses to the survey were anonymous, and results were presented so that none of the participants were identifiable. The survey included 18 questions, with an approximate completion time of 10 minutes.

### **Data Analysis**

My data analysis process included preparing the data, organizing it with codes, and then identifying core themes. I chose a coding process because my data, including both the interviews and the survey responses, are comprised primarily of open-ended text responses. As described by Creswell (2016), coding text data is a central skill to qualitative research using open-ended text (p. 152).

I began preparing my data for analysis by converting the recorded interviews and survey results to a digital text format. I prepared the interview data in the form of a word document transcript. The survey data was exported using a Comma-Separated Values (CSV) file and organized according to each survey question in a spreadsheet. I used spreadsheets to develop tables for the survey's statistical portions, such as the demographics and top challenge responses.

Next, I worked to organize the data with codes. I began with printed hard copies of the interview transcripts and the survey's open responses. Following the coding process outlined in Creswell (2016), I prepared the data for coding by reading through each interview and open survey responses at least twice. Each time reading through, I hand-wrote notes in the margins, summarizing key points, concepts, and participants' sentiments. After that, I looked for patterns in the margin notes. Once the patterns began to emerge, I used colored pencils to mark similar codes in the hundreds of pages of data.

As I identified patterns in the codes through this process, I grouped similar codes as evidence of broader categories, also known as themes (Creswell, 2016, p. 153). I logged each theme in a spreadsheet and attached supporting quotations and margin notes. After reviewing and condensing the themes, I organized my findings into four key categories: *Impact on Presence*, *Impact on Operations*, *Impact of Communication and Collaboration*, and *Impact on Morale*. These categories are identified in detail in the Findings section.

Finally, I analyzed my findings through the lens of the Change Theory Model of Managing Transitions by William Bridges (1991). I had not originally planned to use Change Theory. When starting the research and collecting data, the pandemic was viewed as a temporary pain point and putting services on hold until the threat of spread had lessened. As the year progressed and we experienced several worsening waves of outbreaks, with the fallout of the crisis dragging on for so long, it became apparent that things were changing. We began talking about how the "new normal" would look.

### **Validity and Reliability**

My intention in this research was to use methods which stand up to scrutiny and have credibility. At the same time, I acknowledge challenges to validity and reliability in this research design. Reliability is the extent to which the instrument produces a consistent result and validity is measuring what is intended while eliminating other possible casual factors (O'Leary, 2017, p. 83-84). The validity of this study is challenged right away by the fact that I am using non-random, convenience sampling of participants.

It was difficult to separate the personal impacts I experienced from the pandemic from the data analysis. I captured my pandemic experiences in my reflexive statement to help the reader understand my biases and consider those biases in my analysis. The reader should also

understand that my professional network within the Minnesota hospice community may have skewed the data, both in who responded (i.e., those who know me professionally) and how they responded. To decrease the likelihood of researcher bias, I engaged in regular self-reflection, peer debriefing discussion with my classmates, as well as external auditing by my instructor and research advisor.

One step I took towards increasing validity and reliability in my study was to use the Phased Approach of designing the survey based on the initial interviews (O'Leary, 2017, p. 168). By utilizing multiple sources of data as evidence, I established more robust themes using triangulation (Creswell, 2016, p. 191). This helped to produce a more consistent result to improve reliability. Within the separate interviews and the survey, I asked similar questions in different ways to increase the validity of the data and challenge my own biases. I asked clarifying questions in the interview to learn more about the participant's viewpoint and use what was discovered in the leader interviews to inform and design the staff survey for increased validity.

### **Ethical Considerations**

This study was approved by the St. Catherine University Institutional Review Board (IRB) at the Exempt level to use human subjects in research. Participation in the study was voluntary with no adverse effects should someone choose not to participate. Interviewees and survey participants gave their consent before taking part in the study. All participants were informed ahead of time of the purpose of the study, about how much of their time it would take to participate and how the responses would be recorded. All participants had the choice to opt out of continuing at any time.



Throughout my research process, I adhered to all aspects of my approved IRB application. I ensured that each participant had given their informed consent, knew all of the risks, and understood they could opt out of the research at any given time. I was explicit and detailed about how I handled their data and how I would ensure their confidentiality, as described in this section.

## **Findings**

Through analysis of the two data sets, the interviews and survey, four categories of findings emerged: *Impact on Presence*, *Impact on Operations*, *Impact of Communication and Collaboration*, and *Impact on Morale*. Within each of the categories are supportive themes which are revealed in the two data sets. In this section, I will detail each category and themes with examples from the data to address my research question, "What impact has the COVID-19 pandemic of 2020 had on the hospice care industry in Minnesota?"

### **Impact on Presence**

I use the term Presence here to mean the physical presence of hospice workers with their patients. Overwhelmingly, each participant in this study spoke to the significant loss of physical presence during the pandemic. When safety restrictions prevented hospice workers from being present with their patients and each other, the impact was felt deeply within the industry. In the interviews and the surveys, the loss of presence was experienced in various ways, namely, in the care for patients and families, how families could be together, and how hospice teams functioned.

#### ***Hospice Presence with Patients and Families***

The pandemic deeply impacted the ability of hospice workers to be physically present with hospice patients and families. One interviewee pointed out how presence is the "hallmark of

hospice care," and another interviewee described hospice care as traditionally "Low tech, high touch." The survey data reflected the impact of lost presence in two different tables, Table 2 and Table 3. The two survey questions probed respondents to identify the top challenges they faced. The top challenge identified was "Changes in the ability to be physically present for patients and families."

**Table 2***To What Degree Have the Following Challenges Impacted Your Work as a Hospice Provider?*

Answer Choices	Not at All		Somewhat		Average		Very		Extremely		N/A	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
Changes to how Personal Protective Equipment (PPE) is used	0	0.0	21	16.4	20	15.6	54	42.2	30	23.4	3	2.3
Shortages in Personal Protective Equipment (PPE) supplies	10	7.8	23	18.0	26	20.3	40	31.3	21	16.4	8	6.3
Communication of infection control procedural updates to all staff	18	14.2	22	17.3	22	17.3	39	30.7	23	18.1	3	2.4
Changes to the admission process (e.g. who can be present and how paperwork is processed)	4	3.2	16	12.8	13	10.4	36	28.8	27	21.6	29	23.2
Changes to average length of stay in hospice	27	21.4	15	11.9	40	31.8	22	17.5	4	3.2	18	12.5
Changes in the ability to be physically present for patients and families	0	0.0	5	3.9	10	7.9	33	26.0	78	61.4	1	0.8
Changes to the full interdisciplinary support experience for patients and families (limits on auxiliary services and special programs offered)	0	0.0	2	1.6	5	3.9	27	21.3	93	73.2	0	0.0
Using more telehealth and telephone calls to provide care	2	1.6	15	11.8	25	19.7	60	47.2	20	15.8	5	3.9
Managing care facility/congregate living restrictions on visitors	2	1.6	2	1.6	10	7.9	43	33.9	64	50.4	6	4.7
Impact to patient quality of life	1	0.8	2	1.6	5	3.9	39	30.7	79	62.2	1	0.8
Impact to caregiver strain	0	0.0	0	0.0	4	3.2	40	31.5	80	63.0	3	2.4
Conducting team meetings virtually	11	8.6	27	21.1	39	30.5	35	27.3	13	10.2	3	2.3
Changes to overall interdisciplinary team communication and team cohesion	6	4.7	23	18.0	29	22.7	48	37.5	20	15.6	2	1.6
Impact to hospice staff morale, job satisfaction, and work-life balance	2	1.6	8	6.3	16	12.5	45	35.2	56	43.8	1	0.8
Other	0	0.0	0	0.0	0	0.0	2	8.0	10	40.0	13	52.0

**Table 3**

*From Your Perspective, What Were the TOP THREE MOST Challenging Conditions for Your Organization During the COVID-19 Pandemic So Far?*

Answer Choices	Top 3 choices	
	<i>n</i>	%
Changes in the ability to be physically present for patients and families	71	55.5
Changes to the full interdisciplinary support experience for patients and families (limits on auxiliary services and special programs offered)	64	50.0
Impact to patient quality of life	56	43.8
Managing care facility/congregate living restrictions on visitors	45	35.2
Impact to hospice staff morale, job satisfaction, and work-life balance	29	22.7
Impact to caregiver strain	26	20.3
Shortages in Personal Protective Equipment (PPE) supplies	22	17.2
Communication of infection control procedural updates to all staff	16	12.5
Changes to how Personal Protective Equipment (PPE) is used	15	11.7
Changes to the admission process (e.g. who can be present and how paperwork is processed)	13	10.2
Using more telehealth and telephone calls to provide care	12	9.4
Changes to overall interdisciplinary team communication and team cohesion	8	6.3
Changes to average length of stay in hospice	4	3.1
Conducting team meetings virtually	2	1.6
Other	1	0.8

**Interdisciplinary Support.** Changes to the full interdisciplinary support experience for patients and families was another challenge identified by the participants. These changes were

related to external and internal factors with their organization. External factors included restrictions from congregate care facilities, state-mandated restrictions, and individual homes limiting visits. Internal factors included limiting the full interdisciplinary support related to staff furloughs or other organizational choices to limit non-nursing disciplines' role from visiting patients in person.

Interviewees and survey respondents spoke to frustration with congregate care facilities limiting visits to only nurses, if they allowed anyone from hospice at all. These restrictions prevented other supportive services such as social work, chaplaincy, home health aide, music, and massage therapies from being directly involved in care. Patients in private homes also limited the number of visitors due to concerns about the virus.

**Impact to Quality of Care.** Interviewees and survey respondents expressed deep concern about how restricted presence impacted the quality of care they provided. There were fewer eyes on a patient, which could affect safety and quick response to comfort needs, and it puts more burden on the day-to-day caregivers. Survey responses identified top challenges around the impact on patient quality of life and caregiver strain as their supportive presence was heavily restricted. One interviewee noted, "Hospice is very, very human and very intimate, and unfortunately technology and phone calls and things like that don't replicate that intimacy as well as in-person presence." Many participants expressed concern that isolation procedures would become more common as a result of this pandemic.

### ***Family Presence with Hospice Patients***

Interviewee and survey respondents emphasized the impact of visiting restrictions on patient quality of life and caregiver strain. By limiting visits, patients and their caregivers were more isolated. Several survey respondents expressed frustration with how the visitor restrictions

and isolation appeared to cause more harm than good and wished that there was more support to get hospice care services in the door.

Many participants noted how visitor restrictions complicated the already difficult grief and loss associated with a loved one's death. One survey participant shared an example:

It has been emotionally exhausting taking care of patients, especially in facilities where the family could not visit. In one case of an actively dying patient, I did a FaceTime visit with family members to say goodbye to their mom and grandma. The son visited through the window as I held up the phone to his mom so she could hear his voice. I should not have been the one holding her hand as she passed while her son was out the window.

There have been many experiences like this one. It has been traumatizing for the workers, patients, and families.

Others mentioned the lack of in-person gatherings, like funerals, to grieve a loved one's loss.

Bereavement counselors noted a dramatic increase in demand for their virtual support services due to more intense and complicated grief associated with the pandemic.

As a result of facility visitor restrictions, participants noted an increase in families attempting to care for hospice patients at home. “Right now we are seeing more families taking their loved ones home to care for them, mainly because the children are able to work from home,” one survey participant pointed out. Others expressed concern about hospice patients' safety at home, with caregivers more isolated and with less support than they would have with a facility. One participant pondered the long term impacts of facility restrictions, “I think there will be less hospice in facilities as families are pulling their loved ones out due to isolating restrictions that will remain for a long time.”

### ***Presence as a Hospice Team***

The loss of physical presence impacted the work setting as well. Participants expressed feeling a great sense of loss with their team cohesion. Required interdisciplinary team (IDT) meetings were now held by phone or virtual meeting platform. One interviewee with decades of hospice leadership experience posited, “We’ve always had in-person IDTs and had to move to complete remote meetings, and that’s a loss. So how do you fill the gap of that support that naturally happens when you’re in the presence of other team members?” They noted the leadership challenge of keeping on top of staff needs and attending to their wellbeing. Without face-to-face meetings or seeing staff in the office, they cannot read body language to see if they need support or encouragement, if they are upset or unwell. Staff expressed similar concerns about keeping up with their teammates.

### **Impact on Operations**

The data also revealed a finding related to the impact on operations. By operations, I mean the systems and process work of managing the hospice business. As the pandemic raged on, many business operations changes occurred in an effort to balance safety and quality of care while meeting regulatory requirements. The leaders I interviewed were particularly concerned with these issues as they maintained business operations. Hospice staff struggled to keep up with these changes as they were occurring. Both groups wondered which of these changes would be temporary and which would have a lasting effect. The top themes relating to the pandemic’s impact on hospice business operations are safety protocol and resources, staffing challenges, adoption of technology, congregate care relationships, and financial challenges.

### ***Safety Protocol and Resources***

Hospice care involves certain safety protocols and resources. Specifically, this includes infection control procedures and access to the equipment to keep staff and patients safe. At the

time of the survey, operational efforts to better procure and distribute personal protective equipment (PPE) were still developing. Interviewees and survey respondents spoke to the challenges of accessing resources to operate safely and adjusting infection control protocol during the pandemic. They also offered predictions about what infection control protocol and resources might look like in the future. At the time of the survey, operational efforts to better procure and distribute PPE were still developing. Both leaders and staff experienced resource challenges.

Leader interviewees noted the challenges of accommodating the sudden need for much more PPE supply than they usually stock and using PPE more with every visit. Some emphasized the anxiety of maintaining enough supply and the correct type of PPE, especially in the early days of the pandemic, "...is it going to run out, are we going to have it, is this the right stuff?" Leaders discussed the challenges of repeatedly adjusting infection control policies to follow national guidelines while working with the limited supply available to their organization. One leader stated,

In the beginning it was day-to-day, we were listening to hours and hours of phone calls, trying to figure out what we were supposed to do and how we were supposed to do it, and then not necessarily having the equipment we needed in terms of PPE to provide that layer of safety for our staff.

Many staff survey respondents expressed frustration with the lack of resources, especially PPE. They mentioned the changing protocols with masks and reused them more often than the staff was originally trained due to shortages. One staff survey respondent shared, "Due to N95 shortages, we have to keep re-testing people for the masks because we can't get a constant



supply of the same type of mask. We run out of one style, and they have to re-test everyone to the new style [of mask, to ensure it was safe to use].”

Survey respondents and interviewees noted the difference between organizations when it came to procuring resources. Some survey respondents noticed, in the field or through conversation, how other hospice programs supplied and utilized PPE differently. One participant mentioned that their small hospice organization’s budget could not keep up with PPE needs. At the same time, another shared that the larger health system they worked for did not seem to prioritize enough PPE for their hospice division. Leaders noted how helpful it was to collaborate through the state network to share strategies for procuring and distributing PPE.

Even with the changes and efforts underway at the time of data collection, there was still work to be done. When speaking to what was left unresolved at the time of participating in the study, participants noted that testing and PPE supplies remained inadequate at this point in their experience. They were waiting for a vaccine. Most participants predicted permanent changes to infection control protocol and PPE supply chain changes as a long-term result of the pandemic. Some wondered if masks would ever go away. Other predictions included frequent testing and screening of patients, care home visitors, and staff as a regular protocol. Many expressed feeling there would be generally more awareness of infection control by health care workers and the general public. Others wondered about preparing for “the next virus” with better emergency and disaster planning.

### ***Staffing Challenges***

Hospices experienced several staffing challenges during the pandemic. In addition to challenges caused by visit restrictions, other staffing challenges were caused by the pandemic. Many programs were understaffed due to a general sense of caution, work accommodations, and

furloughs. The impacts experienced by the industry were overburdened staff who remained working and the possibility of workforce changes in the future.

**A Sense of Caution.** Hospice field staff demonstrated wariness to work in the community during the early days of the pandemic. A few leader interviewees shared experiences where some direct-care staff resisted work generally because of fear of the unknowns about the virus or feeling they did not have adequate protection to do their jobs safely. Staff, understandably, did not want to contribute to the spread among the frail communities they served, nor did they want to put themselves or their loved ones at risk. One interviewee noted, “There were elements of discrimination that we had to face, like ‘I don’t want to care for this person because of COVID.’”

**Work Accommodations.** Some hospice employees sought work accommodation during the pandemic. Reasonable workplace accommodations were an option for individuals with an underlying health condition which may put them at greater risk of severe illness from COVID-19. Leader interviewees discussed the challenge of balancing patient visit needs with employees leaving the staffing pool due to job accommodations. Some staff needed an accommodation from their usual roles and were redeployed to other areas of the organization. Each of the leader interviewees struggled to be fair to all employees and not overburden remaining staff who are not medically high risk. “How do we run a program and be fair to the individuals who don’t have those health conditions...but keeping the others who do safe, keeping them from doing in-person visits? That’s really challenging.”

**Furloughs.** One of the most troubling challenges of the pandemic which leaders and staff experienced was employee furloughs. Furlough, unlike a permanent layoff, involves a forced leave from work, often without pay. Some furloughs required reduced hours and others involved

months away from work. Furloughs were used as a way of cutting business costs during the pandemic. Leaders identified the tremendous amount of stress on their leadership teams to “grapple with really, really hard decisions that we know are effecting peoples’ livelihood, and particularly, people who have such a significant impact on care and service delivery.” Another leader stated that the mandated furloughs, layoffs, and pay cuts felt, at times, “unnecessarily cruel.”

Many staff survey respondents expressed distress about the furloughs and how some staff were deemed “non-essential” to hospice business operations. Additionally, hospice staff respondents noted how differently hospice agencies handled staffing and furloughs. Not all programs furloughed their staff. Some of the furloughed employees expressed feeling left “high and dry” and ultimately neglected by their employer. In contrast, some noted feeling supported by their employer while they were out on leave. One staff participant shared,

Furloughed staff have received continued benefits, free meals, \$50 in grocery reimbursements, and many have been redeployed within the system. Spiritual care offered daily phone counseling for our staff as well as for families and patients. [A program in our organization] offers a daily phone meditation for staff.

Some employees were furloughed for long periods, while others were required to take short periods of furlough throughout the summer. Rotating furloughs created a sense of disorder as the teams tried to remember who was available and who was off. “It creates a strain on staff to provide adequate attention to each patient and family,” one participant said of the rotating furloughs. One leader expressed concern about when would they be able to bring staff back from furlough, “Oh, maybe we’ll be done in a few months or something...we keep kicking the timeline down the road.”

**Overburdened Staff.** Of those staff who were able to keep working, many of them felt overburdened with the workload. Being overburdened meant taking on a much higher caseload of patients and having to meet all patient needs without the support of the full hospice interdisciplinary team. Several staff survey respondents mentioned the pressure to take on more patients without the adequate staff to support those patients safely, “We were so short-staffed in some cases, and our nurses had to take on more patients than usual.” In particular, participants noted the extreme burden on nurses as other disciplines were barred from seeing patients in person. One participant said, “Our nurses felt so isolated, and as though they were carrying the weight of the care team for so long, they were the only staff allowed to be in the same room as our patients.”

Several respondents pointed out the organizational choices that made the burdens of the pandemic worse. For some, this included a tightening of staff resources, “Staff have been reduced, which severely impacts an already wounded morale.” “They increased the expectation of productivity during this crisis while not filling positions that were vacated,” one person said.

**Changes to the Workforce.** A large portion of participants, both survey respondents and interviewees, anticipated a change in the people who serve in the hospice industry. Prior to the pandemic, the hospice workforce was robust with many different professional, clinical, paraprofessional, and volunteer roles. Several interviewees and survey participants mentioned staff or volunteers leaving the field, whether due to burnout or changes to the industry or because of health concerns. In the survey, one participant said, “I wonder if we might see a permanent change in the Medicare requirement for volunteers doing 5% of the care. It is much harder to find volunteers who are willing to visit right now, and many have resigned.” A leader pointed out

that most of their volunteer population is over the age of 70, therefore, more high risk in terms of COVID harm.

One survey participant wondered if workers of certain disciplines might leave, either temporarily or permanently,

I think that large volumes of massage therapists, music therapists and chaplains will leave the profession and/or the population permanently (I know several who have). This may not be permanent, but I think it will take time for these disciplines to be as widely available again, as they were before the pandemic.

Another wondered about how many nurses would stick around, “I think organizations will continue to burn out the nurses and think they can function with less staff.” A leader interviewee had a similar concern about the staff who obtained job accommodations due to higher health risks, “COVID is not going away...I think nurses within hospice and other areas like home care are really going to have to do some soul searching if they have some of these high-risk health concerns that will prohibit them from doing the bedside care.”

### ***Adoption of Technology***

Another significant operational challenge both interviewees and survey participants identified was the rapid, forced shift towards more distanced support methods, using more technology, and going paperless to maintain connection and organizational function. Prior to the pandemic, many hospices continued to use paper forms and documentation in some settings. During the pandemic, the appropriate technology was needed for patient care through virtual visits, to lead Medicare-required interdisciplinary team meetings, and to provide staff support.

While all hospice programs had long since begun transitioning towards more remote and paperless technologies, the leader interviewees all expressed frustration with this sudden push

towards majority-telehealth and majority-paperless operations. This dramatic change involved training staff at a time when all were highly stressed and unable to learn together in-person. Interviewees who were leaders in large health care systems lamented the slow uptake of new technologies. In contrast, leaders of the smaller organizations lamented the high financial cost of adopting these new programs. Additionally, they noted the challenges of connecting remotely with this particular population of elderly or economically disadvantaged clients.

Survey respondents expressed frustration with the industry's slowness to adopt new technologies for remote work. A few noted that, when forced to work from home or in a paperless manner, the technology needed was not in place at their organization. "I wish they would have implemented Docu-Sign or a different form of electronically signing for hospice admissions forms," one participant lamented.

Telehealth was another significant frustration for staff. Some mentioned their organization did not have any telehealth platform ready, or the telehealth program they had available was insufficient. A few said, when their organization did roll out a telehealth program, the training was inadequate.

While the sudden roll-out of new technologies was painful for some, others expressed hopefulness about this change. Many pointed out that telehealth and other types of video calls will help better connect families who are geographically distanced from one another, that telehealth will reach more patients in rural areas, or when the weather makes it unsafe to travel. "When I think about our winters that we have in Minnesota, having that technology to be able to connect with a patient and family when we can't get there quickly in the car, it will serve us well into the future," one leader commented. Another celebrated, "For an older person to not have to

get up, get dressed, and drive somewhere and sit in a waiting room...that would be such a positive thing.”

When musing about what might permanently change with the hospice industry, one of the most common responses was that virtual and remote work was here to stay. Participants pointed out how the pandemic demonstrated our ability to work from home, requiring less brick-and-mortar office space. More paperwork can be completed and submitted electronically. Participants anticipated that more team meetings would be conducted virtually, even after the pandemic is resolved.

### ***Congregate Care Relationships***

Hospices rely heavily on functional relationships with congregate care facilities, like nursing homes and assisted living facilities, to operate successfully in the community. Every interviewee who participated discussed at length the challenge of getting in the door with their partnering congregate living facilities. Some pointed out how the restrictions in who could enter reflected an old hierarchy in the health care world, reinforcing old stereotypes of who was the more “essential” type of care provider. Most interviewees noted the inconsistencies between each facility’s response to the pandemic and how their requirements did not always mesh with the needs of their hospice organization or health system, “everybody had a different idea on what the right thing was to do.”

Most frustrating for the interviewees was how the facilities did not comply with the direction of the state Department of Health and federal Centers for Medicare and Medicaid Services (CMS) guidelines. Those guidelines stated that hospice was an essential service to their residents and that this service must be accessible to their patients. Referencing the facility screening protocol, “If [our staff] had visited a COVID-positive patient earlier that day, even if

they were wearing appropriate PPE during that visit, they were not allowed to enter the next facility they went to.” One leader expressed frustration with other leaders in long-term care, who implemented such harsh visitor restrictions during this time in the pandemic and were unwilling to compromise:

Although they mean well, essentially their actions have resulted in them restricting our patients from having access to a benefit that they’re entitled to, a particularly powerful benefit in bringing comfort and peace to patients at end-of-life. We have seen, through the stories our employees have told, such poignant moments when one of our patients is dying, and the family was unable to be present in that long-term care setting, how heart-wrenching that was for the patient who is dying, as well as those family members? Where else do you get that emotional support, that unconditional love? Where else do you get it, if not from your family?

Another leader expressed feeling compassion for nursing home leaders, “We don’t even have half of it to deal with as the nursing homes...I can’t imagine having that kind of burden as a leader...[they] are getting just beaten by the press and by their communities, which is really unfortunate.”

While some leaders and staff expressed concern that facility relationships might become more strained, others hoped the relationship might become more collaborative. One leader pointed out their hope that hospices collaborate more with facilities in the future, especially around emergency preparedness:

A facility is required to have its own crisis response program. Then we’re required to have our own, but then we don’t always talk and make sure they mesh and how important that would be, especially on a state or larger level, just to make that more of a standard,



maybe to be more collaborative in our crisis response rather than these separate little entities that are all just having an individual crisis and making it worse by not being collaborative.

### ***Financial Challenges***

All of the leaders expressed concern about potential financial challenges as a result of the COVID-19 pandemic. While they did not discuss their own organization's financial challenges, the leaders did express general concerns about quality scores, reimbursement, and regulation issues. Each anticipated it would take years to recover from the economic impact of the pandemic.

**Quality Scores.** Hospice programs rely on quality scores, which are linked to reimbursement and future referrals, to remain competitive in the hospice marketplace. Lower scores would potentially cause long-term harm to the business as families and referral sources can see the organization's ratings posted through the CMS website (at the time, called Hospice Compare). The leader interviewees wondered about the potential impact of pandemic-induced operational changes on their quality scores. A few leaders expressed concern that with visit restrictions and staffing challenges, the quality of care patients and families experienced was not up to their standard. Family surveys, sent out after the death, could reflect lower quality care scores.

**Reimbursement and Regulation.** Reimbursement and regulation are two significant aspects of health care operations, and hospice relies on CMS to dictate requirements for both. Several of the leaders wondered about changes to CMS reimbursement and regulatory requirements. At the time of the interviews, CMS had recently expanded coverage to include

telemedicine as a billable patient contact type. CMS had also provided a waiver for hospice volunteer visit requirements during the pandemic.

The leaders wondered what changes might occur after the pandemic. One leader expressed their concern that CMS might change how they reimburse for collaboration with congregate care facilities. They pointed out that CMS had for years considered lowering reimbursement rates or changing how hospice care is provided in congregate living settings. Now during the pandemic, CMS had a plethora of data to show how patients could be cared for with minimal hospice staff presence in these settings.

### **Impact of Communication and Collaboration**

Communication and collaboration were vital to success during the pandemic. Communication is defined as the exchange of information, and collaboration is defined as working together to accomplish something. When communication was poor, or collaboration was lacking, hospice organizations and their members suffered. Whether it went well or went poorly, participants addressed communication and collaboration in their responses. This category's findings focus on communication and collaboration within the hospice organization, the state's professional network, and the state government.

### ***Hospice Organization***

Staff survey responses varied widely on how their hospice organization handled communication during the pandemic. The hospice organization is defined as the individual hospice business represented by the study participants. Leaders felt challenged in how they delivered effective communication with such rapidly occurring changes. They scrambled to keep up with state and federal guidelines, interpret them, enact changes, and communicate those changes to remote staff. Most of the study participants, staff and leaders, noted how difficult it

was to keep up and understand all of the new information. Organizational communication efforts were at times too much or not enough.

Negative comments about communication in the data described inconsistent, conflicting, or confusing information about changes in protocols and recommendations. Sometimes announcements did not get out to everyone who needed to hear it, or the omission of certain details left some team members feeling less important than others. Most of the communication concerns in the data had to do with safety and infection control procedures like using PPE and identifying who was allowed to make visits.

Many survey respondents praised their organization's communication during the pandemic. The general theme of this praise was around frequent, consistent, and clear communication from leaders. Many specifically mentioned having an effective system of communication in their organization. Many cited communications that came daily or weekly to all appropriate stakeholders. Positive feedback about communication mentioned email, virtual meeting, phone, or video messages, as well as frequent one-to-one communication with one's direct leader. Timeliness of communication and response to questions were also appreciated. Some pointed out how much they valued their leadership transparency in these messages. Additionally, staff respondents expressed gratitude for the frequent communication their leaders engaged in with their partnering care facilities.

### ***State Professional Network***

All of the leader interviewees and some of the survey participants noted the vital communication and collaborative work within the state's professional network. The state professional network is defined as any collaborative relationships within the Minnesota hospice industry, outside of the individual hospice business. The Minnesota Network of Hospice and

Palliative Care (MNHPC) was often mentioned as a strong organization whose efforts made surviving the pandemic easier. One interviewee said, “I think we’re really fortunate here. We have a wonderful group of leader providers within the Metro area, but also across the state.”

Interviewees pointed out how MNHPC hosted regular online meetings, virtual committees, and electronic message boards to keep members of the hospice industry connected. As an example, one of the committees mentioned was focused on standards of practice or best practices in the time of COVID-19. Interviewees also talked about the education initiatives through webinars and sharing of virtual updates and resources. Each physician who responded to the survey highlighted how helpful it was that the state’s hospice and palliative care physicians hosted frequent remote meetings to address acute issues. Many participants expressed feeling connected and validated by these efforts that they were not alone in these struggles.

All leader interviewees noted the impact of the state network’s collaboration and advocacy on their relationship with the Department of Health. A few participants said that they, as a group of leaders, put together a list of questions to bring to a meeting with the Department of Health to help advocate for getting back into congregate living facilities. It was no small effort. One participant said in their interview,

It did seem like it took a while for the Department of Health to really crack down on the facilities that were not letting us in. We were like, hey, this is an essential thing. This is actually a vulnerable adult issue if you are not letting the hospice nurse in...It was interesting to see how it worked out.

They also learned from each other that the Department of Health was making its rounds among the hospice programs to conduct infection control surveys, right about the time of the interviews conducted for this study.

Industry competition did at times get in the way of effective collaboration. Several noted that it would have been beneficial if the other hospice organizations in the state collaborated more to share COVID-19 testing strategies and resource sharing. “I think we are still too focused on keeping our own patients rather than sharing resources,” one participant said.

### ***State Government***

The state government's communication and collaboration efforts were at times successful, and at other times they fell short, according to participants. The state government in this context includes the governor, the legislature, and the department of health. Participant responses regarding governmental challenges largely centered on legislation and the enforcement of protocols. They praised Governor Tim Walz and the Minnesota Department of Health while condemning the state legislature for politicizing the pandemic.

Participants appreciated the governor's communication and leadership. They described how the governor partnered with the department of health to educate the public using data-driven and science-based communication. Several study participants noted the helpfulness of the governor's daily 2:00 PM updates with clear visual aids when the pandemic response was most rapidly changing.

Some state efforts went well and others did not. The state responses that participants felt were most productive were the shelter in place orders, closing of certain businesses, and moving schools to distance learning. More specifically to their work as hospice staff, participants expressed gratefulness for the roll-out and enforcement of the "essential visitor" policy with care facilities, allowing hospice staff and a limited number of family members to visit despite other restrictions. Many mentioned wishing they had more state support to clarify expectations and enforce provisions to allow families and hospice workers access to see dying patients. "I wish

some more thought had been going into the impact and very real risk that isolation has on geriatric and chronically ill populations."

Many respondents expressed frustration with the state legislature, politicizing the pandemic and pushing to lift restrictions too soon. They also noted inconsistencies with what was shut down and what was not, all while putting their patients more at risk. One participant shared, "I condemn the legislature for the ways they have been obstructive and destructive of the COVID-19 virus plan and have contributed to increased illness, deaths and prolonged life of the virus because of it."

### **Impact on Morale**

One of the most significant impacts revealed by the data is the impact to industry member morale. Morale is defined as a sense of confidence, purpose, and well-being as an individual or together as group working towards a common goal. This impact was felt by both staff and leaders, although their perspective on the issue at times differed. Morale was challenged in many ways during the pandemic. There were also many positive perspectives gained by the experience. Morale was impacted by fear and anxiety, fatigue and burnout, mission and purpose, as well as creativity and resilience.

### ***Fear and Anxiety***

Fear and anxiety were often mentioned by study participants when reflecting on their experience of the pandemic. Early on, fear of the unknown was a challenge. One leader interviewee identified the flight, fight, or freeze response in their staff. They were "just blaming things, blaming each other, blaming the organization, people being a little shorter than they normally are...Other people, I think, were just really paralyzed, unable to process information, unable to really respond to the situation."

Several participants expressed anxiety driven by a loss of trust. Some had lost confidence that the general public would change their behavior to curb the infection rates. Some conveyed losing faith in the country's leadership. Many mentioned the disappointment of public ignorance and divisiveness on the issue of the virus. "There is still a divide between those who will and will not wear a mask..." one pointed out.

The emotional toll of not being able to perform one's job well also contributed to a general level of anxiety. Of the staff who were capable of making safe visits, many could not because of facility restrictions or families asking to limit visits. Several interviewees noted their team expressing angst and frustration, knowing they could not access their patients and care for them in a valuable way. They noticed the emotional toll on staff who felt they could not provide high-quality care to their professional and ethical standard. Both staff and leaders expressed feeling the impact of secondary trauma and unresolved grief, knowing that family members could not effectively comfort their dying loved ones and find closure by saying goodbye.

A few interviewees emphasized how the financial impact of the virus fueled anxiety. Staff furloughs created an atmosphere of wondering, "what if I am next?" and wondering if temporary furloughs would lead to permanent layoffs. Some respondents expressed a wish that their organization was more financially transparent. Several interviewees pointed out the clear emotional impact of certain staff being labeled "non-essential." One participant saw how the label caused many staff to question themselves and their role "Am I still needed, am I still important, am I still making a difference?"

### ***Fatigue and Burnout***

At the time of the interviews and surveys, fatigue was setting in. Words like "tired," "stressed," "scared," "exhausted," "sad," and "frustrated" were echoed throughout the

comments. One respondent shared that they felt they were working “in a war zone.” Another comment simply stated, “It’s been hell.” Burnout was mentioned a number of times, and hospice workers were left wondering if they could keep it up. Workers who had been resilient in the past were now struggling. One survey respondent said,

In my two decades of hospice work, there have been things that sometimes tired or frustrated me. There have been times when I felt tired. But I never felt burned out. Not completely. Even if I did sometimes, it would pass. But I feel like this pandemic has completely burned me out. The grief of being cut off from therapeutic relationships, knowing clients were suffering and dying alone, being repeatedly called ‘non-essential’ by people I worked with and around for a very long time, and feeling ignored, have me wondering how much longer I will keep trying to stay in.

Nurses, in particular, were burning out, with much of the patient care falling on their shoulders. One survey participant pointed out, “There was no acknowledgment of the extra burden this all required of the nurses. Many nurses have left because of burnout and feeling torn with duties at home.” Another shared, “Leadership keeps talking about taking time for self-care, and yet we don’t have enough time to stop and go to the bathroom between visits...Work-life balance has never been this hard in my entire career.”

While the leader interviewees noted the impact to morale, burnout, fatigue, and need for self-care in their staff, none addressed those challenges or needs in themselves. Of the five interviews, leaders discussed the concepts of care in the context of the group. They used words like “we” instead of “I” to speak about their organization and their people, but not of themselves or their peer leaders. Leader self-care was not addressed by the interviewees or staff survey respondents.



***Mission and Purpose***

Most of the study participants reflected on the mission and purpose of the work during the pandemic. Leaders and staff expressed pride in the history and calling of hospice work. The hospice leaders expressed optimism that hospice workers had what it took to make it through the pandemic's challenges. Survey respondents expressed more cynicism that the health care industry's priorities were not aligned with patient and worker needs, and would cause harm during the pandemic.

**Optimism.** Some participants expressed optimism about the industry's mission and purpose, feeling that outcomes of the pandemic may be positive for the industry. Most of the hospice leaders I interviewed used reflection to find strength and resolve to lift up their teams during the crisis. They harnessed the pride of the industry's history in dealing with grief and loss and in demonstrating health care industry leadership during past global health crises. Nearly all interviewee participants reflected on the hospice industry's role in the AIDS epidemic and how the hospice mission helped lead the way in dignified care at a time of tremendous fear and stigma. They drew many parallels with the challenges of the COVID-19 pandemic and drew strength knowing that they had made it through past crises just like they would make it through this current one.

Some interviewees pointed out that hospice workers are innately equipped to handle issues of death, grief, and fear. One interviewee mused, "we know this terrain...this is our wheelhouse... it's what we do." One leader went so far as to call the COVID-19 pandemic a kind of "gift" when one looks at the big picture, "...a gift for [all of] us to understand that life is short, and it's important to have conversations with people about what they want, what their goals are,

their advanced directives, and understanding that if you love someone, you will grieve someday."

Several of the interviewees expressed feeling optimistic that the experience of the pandemic will strengthen the industry's commitment to the work. A few others noted how their teams found renewed purpose in the needs of their community. One participant shared, "I had a nurse who came up to me and said, 'This is why I went into nursing, that we are there for people when they need us,' and that was a pretty amazing thing to hear." Another participant thought about it more existentially, "I think there's some kind of resolve that I hope we have in this, that we're just being tested and maybe forged in flames of COVID, that this is my calling and I can weather anything."

**Cynicism.** Other participants expressed cynicism about the industry's loss of mission and purpose and that outcomes of the pandemic may not be positive for the industry. Many staff survey comments mentioned the disconnect they felt between their employer's actions and their values as hospice practitioners. They expressed feeling that the organization's bottom line was more important to their leaders than best practices of care and that the pandemic made this issue ever more apparent. One survey respondent stated,

The pandemic has laid bare the true mission of health care systems which is about making money first and foremost and not about health or care in large measure for its members or its employees. And also the terrible inadequacies of the system and the dire need for a universal health care system not dependent on or connected to people's employment.

Another responded,

I believe the hospice industry has worked very hard to advocate for the patients and families, but in the long run, the rules are more about protecting businesses from lawsuits and not enough about the mental, spiritual and emotional needs of patients and families. Physical needs can be met much of the time, but we humans need much more than that from each other, and that's where we can still improve.

### ***Creativity and Resilience***

All leader interviewees and some survey respondents highlighted the creativity and resilience revealed by the pandemic. Creativity is defined as inventiveness and the use of original ideas to accomplish a goal. Resilience is defined as the ability to adapt successfully in the face of significant challenges and stress. Leaders and teams worked together to lift each other up and keep everyone afloat during the most challenging times. They worked to develop some sort of support system for their teams, and they each highlighted the importance of staying connected. They also put their heads together to innovate new ways of meeting their shared goals.

Every one of the leader interviewees celebrated how their teams dealt with change and how they responded to the crisis. When asked what they learned about their organization while leading during the pandemic, an interviewee replied, "The willingness to do what is right for our patients... we'll find a way to do it. We'll figure it out, no matter the challenges." Another responded that the pandemic "was shining a light on the flexibility and talent of people who do this work...The passion just bubbled up to the top." Several mentioned using creativity to work around the visitor restrictions to connect with and support their patients. Another person pointed out how their organization adapted as they gathered more information, "When things first hit in March, it was difficult to keep up. Now I feel the organization has a more cohesive plan."

A variety of staff support efforts took place to maintain morale. Each leader interviewee shared what their organization was doing to support their staff. Efforts ranged from virtual support groups, weekly wellness meditations, and "gratitude emails" with letters from the families they were serving. The support work's focus was to validate feelings, lift workers up, and "find our purpose again."

In contrast, staff survey respondents had mixed feelings about the support efforts, or lack thereof, at their organization. Poor staffing support was cited most often by survey participants who expressed a general feeling that their hospice organization handled the pandemic poorly. Poor staffing support was perceived as half-hearted or shortsighted attempts by leaders who did not understand the hospice workers' plight.

Positive support efforts came in the form of validation, emotional support, or support to do their job safely. Several pointed out their organizations' efforts to maintain staff wellbeing and keep up morale, and some explicitly pointed out the incredible support they received from their leadership. Several hospice workers mentioned feeling supported by being allowed to work from home. One survey respondent shared,

We were encouraged to take care of ourselves both emotionally and physically. It was OK to take a day off for mental health and re-energize without feeling guilty. They realized if their employees were not OK, the care of our patients would suffer.

### **Summary of Findings**

The purpose of this study was to explore the impact of the COVID-19 pandemic of 2020 on the hospice care industry in the state of Minnesota. Through five hospice leader interviews and 144 hospice staff survey responses, four categories of findings emerged: *Impact on Presence, Impact on Operations, Impact of Communication and Collaboration, and Impact on*

*Morale.* Impact on Presence was felt as a significant loss in the industry, effecting interdisciplinary support and quality of care for hospice patients and families. The loss of presence also impacted families in their grieving process and the hospice team's ability to support one another. The Impact on Operations took the form of changes to safety protocols and resources, staffing challenges, the adoption of new technology, changes in the relationship with congregate care facilities, and financial challenges related to regulation and reimbursement. The Impact of Communication and Collaboration was experienced on the organizational level, within the professional network, and through the government's actions. Lastly, the Impact on Morale was experienced through fear and anxiety, fatigue and burnout, mission and purpose, and through creativity and resilience.

### **Discussion**

In this section, I discuss the research findings through the lens of the Change Theory Model of Managing Transitions by William Bridges (1991). I chose this model due to the pandemic's psychological and social impacts revealed by the data. Additionally, this model fits the nature of the research topic. It speaks to a change that was not chosen or agreed to, can be applied to an individual or an organization, and it supports parallels to the hospice industry's understanding of grief and loss. As discussed earlier in this paper, the Model of Managing Transitions (Bridges, 1991) includes three phases: A Loss, The Neutral Zone, and New Beginnings. I discuss how the findings speak to each phase below.

#### **Loss**

One of the most broadly-felt impacts of the COVID-19 pandemic was the loss of presence. The Bridges (1991) Model begins with a loss and letting go and may include giving up old relationships, identities, ways of thinking and operating. The need for social distancing and

isolation prevented everyone from being together safely (CDC, 2020; WHO, 2020; Harden et al., 2020). Old ways of operating in relationships, from how we celebrate and mourn to the ways we express ourselves, were severely limited or stopped altogether. Everyone was forced to set old identities aside to keep each other safe. Most importantly, our familiar ways of coping with crisis were greatly restricted. Feelings of confusion, anxiety, and fear were common (Asmundson et al., 2020; Pappa et al., 2020; Korkmaz et al., 2020).

The hospice industry collectively felt a sense of lost identity when the pandemic hit Minnesota in March 2020. Previously, the industry's identity revolved around the central theme of presence, being at the bedside of our patients, and communing with patients' loved ones. In the pandemic, industry workers suddenly found themselves scrambling to balance safety with quality care. With the loss of physical presence, what would this look like? Passionate hospice workers felt distressed knowing the care provided to patients was not up to their standard. The traditionally "high touch, low tech" model of hospice care would not work during this crisis. Something had to change.

The full interdisciplinary team, the hospice industry's most vital and valuable component, was suddenly fragmented. This change added to the sense of loss felt by the industry. Visit restrictions, furloughs, and work accommodations forced teams to run a bare-bones operation without their colleagues' support. The old medical hierarchy, which emphasized doctors and nurses over other health care professionals, had taken over, putting an undue burden on nurses and leaving other disciplines wondering if they were needed or appreciated. Some members of the hospice workforce considered whether this was the career for them anymore. Those who stuck it out wondered if their jobs would still be there when visitor restrictions were lifted, but the economy had not yet recovered.

## **The Neutral Zone**

At the time data collection occurred, study participants were in what Bridges (1991) called the Neutral Zone. They were processing the initial losses and exploring what to do about it. What happened in this zone had the potential to spur good changes or cause harm, and the results depended on several circumstances relating to the individuals and organizations involved. Importantly, the ability of the industry to move ahead and eventually gain improved functioning relied on its willingness and ability to be present in the chaos and uncertainty, rather than seek old and familiar patterns of work. All of these circumstances could significantly impact the results of the New Beginnings ahead.

The Neutral Zone is where differences between individuals, like the leaders and the hospice staff, or members of different hospice organizations were made apparent. Leader participants were generally more optimistic, pointing out what was being done in response to the pandemic. In contrast, staff participants were generally more cynical and noted what was not being done. Some participants expressed gratitude for how their hospice organization handled the pandemic and took care of them. Other participants expressed feeling neglected and taken for granted by their organization.

The Bridges (1991) Model expects that individual and organizational functioning would decrease in the Neutral Zone. It is a time of uncertainty and challenges. During the highest levels of functioning in this zone, there is creativity and innovation. At the lower levels, there may be burnout and fatigue. Participants in this study spoke to the variety of states of functioning, noticed in themselves and others in the industry. They also noted differences in how communication and collaboration was handled in the Neutral Zone.

## ***Creativity and Innovation***

Creativity and innovation blossomed during the pandemic, as new ways of meeting patient needs were required. Organizations that demonstrated nimbleness and were not overly bureaucratic could respond more quickly to changing needs. New technologies were quickly adopted to continue business operations, like virtual meetings, paperless documentation, and telehealth visits with patients (Brody et al., 2020). New safety protocols were developed to address PPE shortages and testing strategies, keeping staff functioning as safely as possible out in the community (USFDA, 2020). Organizations also came up with innovative ways of providing staff emotional support, helping them remain connected to the work while also remaining safely distanced. Hospice teams put their heads together to make sure patient needs were met as best as they were able.

### ***Burnout and Fatigue***

Many hospice staff were overburdened and fatigued during the pandemic, particularly nurses (Asmundson et al., 2020; Pappa et al., 2020; Korkmaz et al., 2020). While all hospice workers could be expected to decrease in functioning in the Neutral Zone of this pandemic, nurses were not given the opportunity to be less productive. The demands on their services increased greatly and many experienced professional burnout.

Staff support efforts and their results were mixed in the results of this study. Some efforts failed to achieve their intended effect, leaving staff frustrated and disengaged. Staff expressed feeling supported when their organization recognized and validated the emotional impact of working during the pandemic, and did not just focus on the numbers and processes. Staff appreciated when their relationships were honored and feelings of connection were fostered through creative means, with intention and regularity. Staff also felt supported by organizations



that allowed time away from work, like for mental health days, and appropriate staffing levels allowed them to truly disconnect and have healthy boundaries with the work.

### ***Communication and Collaboration***

Communication and collaboration revealed differences between individual participant experiences, and indicated differences between hospice organizations, during the Neutral Zone. Immediately during and following the loss of presence, communication was difficult for everyone. The many unknowns about the virus and the rapid changes to protocols left everyone's heads spinning, from a governmental level to the individual hospice organization levels.

Communication efforts differed from group to group. While leaders struggled to manage communications, hospice staff experienced frustration with poor communication received on their end. Poor communication was inconsistent, conflicting, confusing, or overwhelming. Successful communication was frequent, timely, consistent, transparent, and concise. Inclusive language was also important for helping all works feel invested in the outcomes of the organization's efforts.

Collaboration efforts were generally experienced as positive by the study participants, especially the collaboration provided by the state professional network. The most important and effective collaborative effort by the state network was advocacy for the rights of hospice patient in congregate care settings, for them to access essential hospice services and not be isolated from loved ones in the last days of life. Another effective collaborative effort through the state network was educational initiatives and informational meetings.

### **New Beginnings**

After being in the Neutral Zone for some time, new ways of being and operating emerge in the New Beginnings phase (Bridges, 1991). At the time of my data collection, the New

Beginnings were not yet realized and participants were solidly in the Neutral Zone. Each of the participants had a chance to comment on their anticipated impacts of the pandemic. Participants mused about possible changes to hospice operations, congregate care facility relationships, and the hospice workforce.

### *Hospice Operations*

At the time of this paper's completion, May 2021, New Beginnings in hospice operations were already developing. During the pandemic, the industry went from "high touch, low tech" to "high tech, low touch" nearly overnight. Additionally, the industry evaluated its capacity for running as lean as possible, with the least amount of staff involved in direct, in-person care. What hospice leaders do with these learnings could impact how hospices operate in the future. The goal will be to balance the new model of remote work with high-quality end-of-life care.

We have seen a significant shift in remote work in the industry during the COVID-19 pandemic. At the time of my data collection, participants explored what remote work looked like for their organizations and their lives. There are now many more options for connecting remotely with patients and families and each other. Becoming more high-tech comes with advantages like less waste of paper, ink, and printing services, as well as less vehicle fuel consumption and emissions from commuting, and less expense on brick-and-mortar office spaces. Most participants had agreed that remote work was here to stay. What is yet to be revealed is how much the industry returns to in-person work.

Still to be evaluated is the ability to safely recuperate hospice presence in the community, perhaps finding a balance as new "high tech, high touch" organizations. Hospice leaders and decision-makers have an opportunity to re-imagine what high-quality care delivery looks like post-pandemic. The new care delivery could look more like the old medical model, one that

continues to put an undue burden on the shoulders of nurses. Or, new care delivery could balance a return to the robust interdisciplinary hospice team experience with the use of advanced technology to fully satisfy the mission of whole-person care across broad geographic areas.

### ***Congregate Care Facility Relationships***

The pandemic severely impacted the relationship between congregate care facilities and the hospice industry, in Minnesota and nation-wide. Participants of this study wondered if hospice relationships with congregate care facilities would be strengthened or strained by the pandemic. The support of governmental actions was necessary to move forward productively and collaboratively with this relationship. I posit that congregate care facility and hospice relationships will require ongoing government involvement.

Families who will need end-of-life care services in the future may choose different care options for their loved ones due to their pandemic experiences. They may choose to keep their family member at home longer than they would have in the past, avoiding the potential of being cut off from their loved ones at a tremendously delicate time in their lives. This change could be a potential boon for the hospice and home care industries.

There is a possibility that Medicare reimbursement for hospice patients in congregate care settings may change due to the pandemic experiences (CMS, 2020). As hospice workers were barred from seeing their patients, nursing facilities were forced to pick up the slack. Medicare decision-makers may reflect on this pandemic and wonder if hospice care services are redundant to what is available to the patient in-house. In uncertain economic times ahead, a change in reimbursement rates for patients in congregate settings may be seen as an opportunity to cut costs.

### ***Workforce Changes***

In the industry's New Beginnings, there may be a change in the population of hospice care workers. The nature of the COVID-19 virus caused many older or medically compromised workers and volunteers to step back from their work out of safety concerns. Some staff and leaders, many of whom were part of developing the modern hospice industry as we know it today, are retiring. Some workers may consider leaving the profession due to burnout. Seasoned hospice professionals may find that the nature of the work they were initially called to has changed too much. The new hospice workforce may be younger, healthier, and able to keep up with demands on productivity and the use of new technology. New workers and leaders may also have a different idea about the mission and values of hospice work.

### **Implications**

The implications of this research are many. The COVID-19 pandemic will continue to affect Minnesota's hospice industry in new ways, long after this thesis is completed. It is difficult to predict what will change and what the new normal will be. We have just begun forming our narrative of what happened, why and how it happened, and what has changed. Many cling to the hope of a "return to normal," back to the same order of business and behaviors. The reality is that this pandemic has shaken us to our core. We have endured many losses in many forms, some of which can never be recovered. We wandered in the painful and confusing Neutral Zone for much longer than we had hoped and experienced extreme lows and harnessed incredible highs. We are just now seeing the glimmers of a New Beginning on the horizon. We are on the upswing of the U-shaped transition.

This research reveals the fundamental interconnectedness of systems, and more importantly, of human beings. While there are many technical aspects of this pandemic's impact, its ultimate problem is a human one. Human actors are trying to solve it, and human actors are

suffering from it. As Kouzes and Posner (2012) say, “Leadership is a relationship.” When we are focused on the bottom line, relationships get short-changed. As an example, relationship-building is not typically considered within the scope of worker productivity. There must be a balance between the two. They must move in tandem and not in opposing directions.

This research is also a call for deep and honest reflection among leaders, with oneself and each other. What did leaders need throughout this experience? What could have helped them to lead with more strength, effectiveness, and endurance? I encourage hospice leaders to consider the decisions they made during the pandemic, their effect on their hospice employees and patients, on themselves and their fellow leaders. Notice how the pandemic was handled differently from one organization to another and how that affected their performance outcomes; what can you learn about your own leadership from this analysis? Also, notice whether trust in your leadership was strengthened or weakened during the pandemic.

Trust is an underlying theme in this experience. Concerns of trust were directed at all leadership levels during the pandemic on the international, national, state, and organizational levels. How much of the anxiety and emotional distress captured in this study was driven by a lack of trust that leaders and organizations had the hospice workers’ and patients’ best interest in mind? As leaders, we have a duty to cultivate trust, to trust others, and act in trustworthy ways.

As we are fundamentally interconnected, accordingly, our ongoing challenge is to take care of one another. We must use creativity and ingenuity to find alternate ways to be safely present for our community's most vulnerable, our hospice patients and their grieving families. Industry, organizational, and unit leaders must structure ways to continue to check in with, support, and provide relief for caregivers of all types; this should happen with intention and

regularity. For example, if hospice staff felt fatigued and burnt out six months into the pandemic, how are they doing now, over a year into the pandemic?

### **Recommendations**

Based upon my research, I make the following recommendations for formal and informal leaders in the hospice industry in Minnesota:

1. The hospice industry should take this opportunity to re-examine and reaffirm its core identity and values. The industry has spent the past 40 years developing an effective and progressive foundation for serving and supporting patients and their families at end-of-life. This industry created work that was practically and emotionally manageable and rewarding for staff while also being fiscally and operationally manageable for organizations to deliver this care.

The leaders and workers who created this industry are reaching retirement. The new leaders may have a different perspective on the mission and values of the hospice industry. The pandemic forces all of us to see that the overall context of care has and may continue to shift rapidly. By clarifying and reaffirming the industry's core mission and values, the industry can work from that foundation to discover and develop innovative ways of delivering on that mission.

2. Leaders in the industry should begin a formal process of examining how changes to hospice operations impacted outcomes: To harvest lessons learned, to celebrate victories, and to account for failures. Note how organizational rigidity or nimbleness effected responses to rapidly changing circumstances. Special attention should be paid to organizational communication efforts, as well as industry collaboration and competition. Additionally, family and staff satisfaction data should be considered.

3. Leaders who supervise direct care providers should consider how they can best support their staff, and themselves, in the face of extreme conditions. This support should include leading staff to call on their core skills of maintaining presence, providing comfort in the face of tragedy and despair, and highlighting those moments of sacredness. Further, they should lead staff to find ways to care for themselves through policies that provide adequate time away from work and staffing support to maintain quality of care while they are away. Leaders should model balanced self-care through their own actions of taking time away, making healthy coping choices, and holding close the mission of the work.
4. Lastly, leaders in the industry must develop an informed and flexible disaster and pandemic response plan. In the 2020, the hospice industry was caught off guard and unprepared to face and operate in a major health crisis that ultimately found hundreds of thousands of people dying alone. Disaster planning should include a solid and consistent system of communication through all levels of leadership. Additionally, planning should include systems for resource management, such as obtaining and distributing PPE, and successfully managing staff shortages.

Finally, I recommend further research on the impact of the COVID-19 pandemic on the hospice industry in Minnesota and beyond. Future research should include a follow-up of staff experiences and perspectives a year or two after the pandemic has resolved. I especially recommend further research into the hospice leader perspective, comparing views of retired or soon-to-be-retired hospice leaders who have been with the industry for decades with the views of newer leaders of the industry. Other important and related topics to study based on the COVID-

19 pandemic are leadership in crisis, trust in leadership, organizational resilience, and career resilience.

### **Conclusion**

The COVID-19 pandemic of 2020 has affected the Minnesota hospice care industry in many ways. The full impact of the pandemic is still being realized as of the completion date of this study. The purpose of my research was to explore the impact of the COVID-19 (also known as SARS-CoV-2) pandemic of 2020 on the hospice care industry in the state of Minnesota. I examined this question from the perspective of the hospice industry members in the state of Minnesota.

In this paper, I reflected on my relationship with this research subject while providing contextual background information. I reviewed scholarly research related to the research subject, including emerging research on the COVID-19 pandemic and how health crisis events in the past impacted the hospice industry. I used a qualitative research approach to collect and analyze data from interviews with five hospice leaders and a survey of 144 hospice staff working in the state of Minnesota during the pandemic.

The research revealed four categories of findings in response to the research question, "What impact has the COVID-19 pandemic of 2020 had on the hospice care industry in Minnesota?" Those categories are: *Impact on Presence*, *Impact on Operations*, *Impact of Communication and Collaboration*, and *Impact on Morale*. I discussed these research findings through the lens of the Change Theory Model of Managing Transitions by William Bridges (1991), using the three phases of transition: *Loss*, *The Neutral Zone*, and *New Beginnings*.

To conclude, we know that the COVID-19 pandemic will continue to affect Minnesota's hospice industry in new ways long after this thesis is completed. I encourage the hospice industry



members to take care of one another, stay true to its mission and values, and shape its New Beginnings accordingly. We have weathered a great storm together. I hope that the learnings gained from this experience will help us be stronger and more committed to helping those facing end-of-life and their grieving loved ones.

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**Appendix A: Interview Recruitment Statement**

Dear, \_\_\_\_\_,

My name is Anna Lee Roberts. I am a Masters' candidate at St. Catherine University in St. Paul, MN, under the advisement of Sharon I. Radd, Ed.D., Program Director and Associate Professor, of the MA Organizational Leadership program. I am conducting a study, titled "The Impact of the COVID-19 Pandemic on the Minnesota Hospice Industry."

I am contacting you, as a leader in the Minnesota Hospice Industry, to invite you to participate in a one-to-one interview for my research study. The interview will take no more than 60 minutes of your time, and will take place via the video conferencing platform of your choice. While I plan to audio-record the interview, the data will be de-identified and any information that can identify you will be kept confidential. There are no foreseeable risks, and there are no direct benefits or compensation.

I will also follow this email with a phone call. If you are interested in participating in my study, I will send you a detailed consent form to review prior to any further participation.

Thank you for your consideration.  
Sincerely,

Anna Lee Roberts, MT-BC  
[alroberts@stkate.edu](mailto:alroberts@stkate.edu)  
952-681-0212



**Appendix B: Hospice Leader Interview Questions and Prompts**

1. Tell me about your experience of leading your hospice care organization during this COVID-19 pandemic.
2. What were some of the biggest and most challenging changes your organization made as the crisis was unfolding?
3. What did you learn about your organization and the way hospice care is provided?
4. How do you think the Minnesota hospice industry responded to the crisis? What went well and what did not go well?
5. In your opinion, what will permanently change in the hospice industry, because of these experiences?
6. What is left unresolved from this experience? What still needs to change?
7. Is there anything else you would like to share?

## **Appendix C: Hospice Staff Survey**

### **Informed Consent**

You are invited to participate in this research project because you have been identified as a hospice worker in the state of Minnesota. The study is being conducted by Anna Lee Roberts, a Masters' candidate at St. Catherine University in St. Paul, MN. The faculty advisor for this study is Sharon I. Radd, Ed.D., Program Director and Associate Professor, of the MA Organizational Leadership program at St. Catherine University.

The purpose of this study is to explore the impact of the COVID-19 (also known as SARS-CoV-2) pandemic of 2020 on the hospice care industry in the state of Minnesota. The survey includes items about your organizational demographics as well as your experience as a hospice worker during the COVID-19 pandemic. The data that we collect from this survey will be used to inform Ms. Roberts' thesis titled "The Impact of the COVID-19 Pandemic on the Minnesota Hospice Industry."

**This survey will take approximately 10 minutes to complete.**

Your responses to this survey will be anonymous and results will be presented in a way that no one will be identifiable. Confidentiality will be maintained to the degree permitted by the survey technology used, SurveyMonkey. Specifically, no guarantees can be made regarding the interception of data sent via the Internet by any third parties.

Your participation is voluntary and your decision whether or not to participate will not affect your relationships with the researchers, instructors, or St. Catherine University. If you decided to stop at any time you may do so. You may also skip any item that you do not want to answer.

If you have any questions about this project, please contact your name and email and/or phone number or the Institutional Reviewer Board Chair: John Schmitt, PT, PhD, 651-690-7739; jsschmitt@stkate.edu

By responding to items on this survey you are giving us your consent to allow us to use your responses for research and educational purposes.

**Would you like to proceed?** [Yes = go on to Question #1, No = go to an end page "Thank you for your time and consideration"]

Q1: Which of the following best describes your role in your hospice organization? [select one]

- ☐ Physician
- ☐ Nurse
- ☐ Health Aide
- ☐ Social Worker
- ☐ Spiritual Care Provider

- Bereavement Counselor
- Volunteer Coordinator
- Therapist (Physical, Massage, Music)
- Administrative support
- Supervisor or Manager
- Other (please specify) [text box]

Q2: About how long have you worked in hospice care? [select one]

- Less than a year
- 1-5 years
- 6-10 years
- 11-20 years
- 21-30 years
- More than 30 years

Q3: What category best describes your organization with regards to **service area**: [select one]

- Mostly Urban
- Mostly Rural
- Mix of both urban and rural

Q4: What category best describes your organization with regards to **size and average daily census**? [select one]

- Small (1-50 patients)
- Medium (50-250 patients)
- Large (250-500 patients)
- Very Large (over 500 patients)

Q5: To what degree have the following challenges impacted your work as a hospice provider?

[Rate for each on scale : 1= Not challenging at all, to 5 = Extremely challenging]

- Changes to how Personal Protective Equipment (PPE) is used
- Shortages in Personal Protective Equipment (PPE) supplies
- Communication of infection control procedural updates to all staff
- Changes to the admission process (e.g. who can be present and how paperwork is processed)
- Changes to average length of stay in hospice
- Changes in the ability to be physically present for patients and families
- Changes to the full interdisciplinary support experience for patients and families (limits on auxiliary services and special programs offered)
- Using more telehealth and telephone calls to provide care
- Managing care facility/congregate living restrictions on visitors
- Impact to patient quality of life

- Impact to caregiver strain
- Conducting team meetings virtually
- Changes to overall interdisciplinary team communication and team cohesion
- Impact to hospice staff morale, job satisfaction, and work-life balance
- Other (please specify) [text box]

Q6: From your perspective, what were the **top three** MOST challenging conditions for your organization during the COVID-19 pandemic so far? [pick three]

- Changes to how Personal Protective Equipment (PPE) is used
- Shortages in Personal Protective Equipment (PPE) supplies
- Communication of infection control procedural updates to all staff
- Changes to the admission process (e.g. who can be present and how paperwork is processed)
- Changes to average length of stay in hospice
- Changes in the ability to be physically present for patients and families
- Changes to the full interdisciplinary support experience for patients and families (limits on auxiliary services and special programs offered)
- Using more telehealth and telephone calls to provide care
- Managing care facility/congregate living restrictions on visitors
- Impact to patient quality of life
- Impact to caregiver strain
- Conducting team meetings virtually
- Changes to overall interdisciplinary team communication and team cohesion
- Impact to hospice staff morale, job satisfaction, and work-life balance
- Other (please specify) [text box]

Q7: As of the date of this survey, how do you feel **Your Hospice Organization**, as a whole, has handled the COVID-19 pandemic so far?  
[Scale Very well to Very Poor]

Q8: Regarding how your hospice organization, as a whole, handled the COVID-19 pandemic so far, what went well? [text box]

Q9: Regarding how your hospice organization, as a whole, handled the COVID-19 pandemic so far, what did NOT go well? [text box]

Q10: As of the date of this survey, how do you feel the **Hospice Industry of Minnesota**, as a whole, has handled the COVID-19 pandemic so far?  
[Scale Very well to Very Poor]

Q11: Regarding how the Hospice Industry of Minnesota, as a whole, handled the COVID-19 pandemic so far, what went well? [text box]

Q12: Regarding how the Hospice Industry of Minnesota, as a whole, handled the COVID-19 pandemic so far, what did NOT go well? [text box]

Q13: As of the date of this survey, how do you feel the **State of Minnesota**, as a whole, has handled the COVID-19 pandemic so far?

[Scale Very well to Very Poor]

Q14: Regarding how the State of Minnesota, as a whole, handled the COVID-19 pandemic so far, what went well? [text box]

Q15: Regarding how the State of Minnesota, as a whole, handled the COVID-19 pandemic so far, what did NOT go well? [text box]

Q16: In your opinion, **what will permanently change** in the hospice industry, because of this COVID-19 pandemic? [text box]

Q17: **What is still left unresolved** from your experience of serving hospice patients during the COVID-19 pandemic? [text box]

Q18: What else would you like to share about your experience as a hospice worker during the COVID-19 pandemic? [text box]